Measurement and Documentation of Complex PTSD in Treatment Seeking Traumatized Refugees

Ph.D. thesis by

Sabina Palic

Danish National Centre of Psychotraumatology, University of Southern Denmark,

Faculty of Health Sciences

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Summary

The aim of the thesis is to study complex traumatization and its measurement in treatment seeking traumatized refugees. Historically there have been repeated attempts to create a diagnosis for complex posttraumatic stress disorder (complex PTSD) to capture the more diverse, trauma related symptoms and personality dysfunction following extreme traumatization. Importantly, patterns of severe traumatic exposure in refugees may represent a group vulnerable to complex PTSD. However, there are currently only a few validated psychiatric measures for the assessment of traumatized refugees, which are limited to measuring symptoms of PTSD, anxiety, and depression. This renders documentation, measurement, and treatment of possible complex traumatic adaptations in traumatized refugees very difficult.

The thesis comprises two studies using different measures and different samples. The first study investigated complex traumatization as Disorders of Extreme Stress Not Otherwise Specified (DESNOS). The first article from this study demonstrated that DESNOS in a clinical sample of refugees, primarily resembled the Schizotypal, and Paranoid personality disorders (PD), when compared to Axis I and Axis II syndromes on self-report measures. A total of 34% of the refugee clinical convenience sample (n = 116) met the criteria for DESNOS, and 32% were estimated to have one of the two PD. Furthermore, Axis-II pathology and DESNOS was observed in traumatized refugees even when there was no presence of childhood maltreatment (which is considered a predominant risk factor for DESNOS and PD). However, there was also overlap between DESNOS and Axis I syndromes – specifically, depression, dissociation, somatization and PTSD. It was therefore concluded, that categorization of DESNOS in refugees under either Axis I or Axis II depends on the overall level of functional impairment and the chronicity of their symptoms. In the second article, 30% of the treatment seeking refugees from the clinical sample

had pathological dissociation 16 years after their exposure to war trauma. - This makes monitoring and treatment of dissociation in the traumatized refugees an important challenge.

The second study in the thesis examined the proposed diversity of psychiatric morbidity in complex PTSD using a global psychiatric measure –the Health of Nation Outcome Scales (HoNOS). Article 3 showed that a group of consecutive refugees outpatients from a Danish specialized clinic (N = 448) had higher levels of global psychiatric impairment than the most inpatients with well-defined diagnoses (e.g. schizophrenia, dementia, addiction, affective, anxiety, and personality disorders). Furthermore, the traumatized refugees had a diverse HoNOS profile characterized by over-all high problems with psychiatric morbidity and functional impairment. This over-all high HoNOS profile was *un*-characteristic of the diagnostically well-defined inpatient groups. Through the use of Rasch analysis, a revised 10-item Refugee HoNOS was developed in article 4. The revised measure displayed good psychometric properties for assessing global, psychiatric impairment in treatment seeking traumatized refugees. Regarding the investigation of complex traumatization, the unidimensionality of the HoNOS in the Rasch model is currently unique to traumatized refugees. It is assumed to be related to the diverse, overall-high HoNOS impairment profile of the traumatized refugees and hence the "complexity" of their condition. Although the thesis explores complex traumatization using different measures, all studies are consistent with the notion of diverse morbidity, indicated by Axis I and Axis II comorbidity, and dissociation. Furthermore the psychiatric morbidity is coupled with high levels of functional impairment. All this renders monitoring of only PTSD, anxiety, and depression in treatment seeking refugees imprecise and probably insufficient for the purposes of treatment implementation and treatment monitoring.

Dansk resume:

Formålet med denne Ph.d. er at undersøge kompleks traumatisering hos behandlingssøgende flygtninge, og hvordan den kan måles i klinisk praksis. - Begrebet "kompleks" posttraumatisk stress forstyrrelse (kompleks PTSD) fokuserer på de meget forskelligartede og ofte personlighedsfunktion- relaterede problemer hos personer udsat for ekstrem traumatisering. Alt imens den omfattende traume-eksponering hos flygtninge sandsynliggør at nogle kan have kompleks PTSD, findes der kun få validerede psykiatriske mål til undersøgelse af flygtninge. Disse måler kun symptomer på PTSD, angst og depression. Dokumentation, måling, og behandling af eventuel kompleks PTSD hos flygtninge er derfor meget vanskeligt.

Afhandlingen indeholder to studier med forskellige patientgrupper. Det første studie undersøger kompleks traumatisering via begrebet Disorders of Extreme Stress Not Otherwise Specified (DESNOS) i en klinisk gruppe af bosniske flygtninge (n = 116). *Artikel 1* viser at DESNOS, når den sammenlignes med Akse I og Akse II syndromer overlapper bedst med Skitzotypal og Paranoid personlighedsforstyrrelse i denne gruppe. Således har 34 % af flygtningene DESNOS, samtidigt med at 32 % også opfylder kriterierne for enten Skitzotypal eller Paranoid personlighedsforstyrrelse. DESNOS og Akse II patologi findes selv hos de traumatiserede flygtninge, som ikke er blevet misbrugt i barndommen. Der forekommer dog også et betydeligt overlap imellem DESNOS og Akse I syndromer - især depression, dissociation, somatisering og PTSD. Derfor konkluderes det, at kategorisering af DESNOS hos flygtninge– under Akse I eller Akse II – vil afhænge af niveauet af funktionsnedsættelse og kroniciteten af symptomer hos den pågældende. *Artikel 2* viser at 30 % af samme flygtningegruppe har patologisk dissociation 16 år efter deres krigsoplevelser. Dette gør monitorering og behandling af dissociation hos traumatiserede flygtninge til en vigtig udfordring.

Ph.d. 'ens andet studie undersøger påstanden om tilstedeværelse af meget forskelligartet psykiatrisk morbiditet ved kompleks PTSD igennem et mål for global psykiatrisk dysfunktion– Health of Nation Outcome Scales (HoNOS). *Artikel 3* demonstrerer, at en multikulturel gruppe af fortløbende flygtningepatienter (N = 448) fra en dansk specialiseret klinik har sværere global psykiatrisk dysfunktion end de fleste indlagte danske patienter med diagnoserne skizofreni, demens, afhængighed, personligheds-forstyrrelser, affektive- og angst lidelser. Ydermere har flygtningepatienter en forskelligartet HoNOS profil karakteriseret ved generelt høj dysfunktion på HoNOS' domæner – både hvad angår psykiatrisk morbiditet og social funktionsnedsættelse. Flygtningenes forskelligartede profil ligner ingen af HoNOS profilerne hos grupperne af indlagte patienter. *Artikel 4* udvikler en HoNOS, der er tilpasset flygtninge, ved brug af Rasch analyse. Artiklen viser, at Flygtninge HoNOS har gode psykometriske egenskaber til måling af global psykiatrisk dysfunktion hos behandlingssøgende traumatiserede flygtninge. Det er interessant for udforskning af kompleks PTSD, at HoNOS er éndimensionel i gruppen af traumatiserede flygtninge men ikke i andre psykiatriske grupper. HoNOS' éndimensionalitet i flygtningegruppen observeres formentligt pga. den forskelligartede – og generelt høje – globale dysfunktion. Éndimensionaliteten kan altså siges at være relateret til "kompleksiteten" af flygtningenes psykiatriske dysfunktion.

Opsummerende, dokumenterer Ph.d. 'ens 4 artikler eksistensen af omfattende og forskelligartet psykiatrisk morbiditet hos behandlingssøgende traumatiserede flygtninge i Danmark. Denne symptomkompleksitet er forbundet både med Akse I og Akse II syndromer, dissociation og høj funktionsnedsættelse. Monitorering af blot PTSD-, angst- og depressionssymptomer i behandlingen af traumatiserede flygtninge udgør formentligt et upræcist og utilstrækkeligt grundlag for at iværksætte en målrettet behandling.

Prologue

My interest in complex posttraumatic stress disorder (complex PTSD) in refugees began a long time before I officially became a researcher of psychological trauma. While I was studying psychology I worked part time as an interpreter in the Bosnian language for a company that provided services to the Central Denmark Region ("Region Midtjylland") and the municipality of Aarhus. Through my work as an interpreter I realized that a number of these individuals were in frequent contact with health and social services. They had frequent visits with the general practitioner, and were frequently treated at the hospitals. Many also had contact with psychiatrists, the mental health services, and social services. The individuals attributed the problems to a "hard life" and often felt misunderstood by the systems that were trying to help them and were wary of their intentions. In the majority of cases, societal institutions did not recognize these individuals as former refugees or that many had experienced trauma on some level. Also, the professionals who *were* aware that these social, familial, economic and violence related problems may be associated to war trauma, often did not know what to do with this knowledge in the wider consideration of the case. It seemed like the "system" was poorly equipped. There seemed to be little systematic knowledge and no "standard" procedures for supporting these individuals. For an outsider it therefore seemed that it was rather coincidental who was offered which kind of help, and who was helped in the end.

At the same time, I observed similar problems in my volunteer work at a drop-in "café" for individuals with mental illness (a part of the social psychiatric system offering social activities for chronically mentally ill individuals). A number of users, who would come to the café, were very socially isolated men with different foreign back-grounds. They were single, often had a very limited social network (or no social network at all) and seemed very impaired in

their interaction with other individuals. It turned out, that many were former refugees, who had been paramilitary soldiers, political prisoners, exposed to torture etc. as young men. They had moved to Denmark without family decades before, and had had problems with occupation and severe social isolation since their traumatic experiences. Many had tried different treatments which seemingly did not help. They led very isolated lives with little social contact.

My observations of war trauma as a very potent force, which disrupts normal life development and for some individuals shapes and permeates all life domains, became more clear to me as I during my studies encountered the concept of complex PTSD. When I started to look into prolonged, diverse trauma sequelae in refugees from a research perspective, I realized why there were such little interventions for these types of trauma-related problems. There was very little scientific literature on the topic in general and little systematic knowledge of these issues in the system as a whole.

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The thesis is based on two studies, the DESNOS and the HoNOS study. Two articles are referred to throughout the thesis as:

DESNOS STUDY

Article 1: Personality Dysfunction and Complex Posttraumatic Stress Disorder Among Chronically Traumatized Bosnian Refugees.

Article 2: Dissociation in treatment seeking refugees in the West.

HoNOS STUDY

Article 3: Norms for Refugee Outpatients and Psychiatric Inpatients on the Health of Nation Outcome Scales (HoNOS) – The HoNOS as a Common Measure.

Article 4: Rasch Validation and Cross-validation of the Health of Nation Outcome Scales (HoNOS) for Purposes of Monitoring of Traumatized Refugees in Western Psychiatric Care.

List of abbreviations

ICD	International Classification of Diseases
DSM	Diagnostic and Statistical Manual of Mental Disorders
PTSD	Posttraumatic Stress Disorder
CPTSD	Complex Posttraumatic Stress Disorder (ICD-11)
DESNOS	Disorders of Extreme Stress Not Otherwise Specified
SIDES	Structured Interview for Disorders of Extreme Stress
SIDES-SR	Structured Inventory of Extreme Stress
HoNOS	Health of Nation Outcome Scales

1 Table of Contents

1. Chapter 1: Introduction

The thesis comprises five chapters. Chapter 1 is a review of complex posttraumatic stress disorder (complex PTSD) literature. It introduces the major concepts and research questions which are investigated in the two studies of the present thesis. Chapter 2 describes the aims and the methodology behind the two featured studies (the DESNOS and the HoNOS study). Chapter three comprises article 1 and article 2, which were composed on the material from the DESNOS study. Chapter 4 comprises articles 3 and 4 which were comprised on the material from the HoNOS study. Chapter 5 is a general discussion of the major findings from the two studies, methodological issues, and future research.

1.1 Literature review

Complex traumatization is used as a generic term throughout the chapter to describe diverse sequelae to psychological trauma, which are not entailed in the diagnosis of Posttraumatic Stress Disorder (PTSD). This chapter explores complex traumatization in refugees within the framework of current diagnoses, or concepts that have been proposed as diagnoses in the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD). These are the Enduring Personality Change After Catastrophic Experience (EPCACE) in the ICD, and the Disorders of Extreme Stress Not Otherwise Specified (DESNOS) in the DSM. The aim of this chapter was to provide an integrative review of the literature about complex traumatization, its central ideas, methodologies, and their relationship to refugee trauma.

1.2 Method

A number of different methods are applied in the integrative review. Firstly, the diagnostic history and central ideas of EPCACE and DESNOS are outlined based on the DSM-

IV sourcebooks, (i.e. official reviews, studies and conclusions of the DSM-IV expert committees). Second, a systematic review of the current DESNOS and EPCACE studies is conducted. Studies of DESNOS in refugee samples are reviewed in detail, and current methodological problems in the field are illustrated. Finally, the results are discussed through a social constructionist perspective, which highlights the major ideological and social misalignments between the PTSD and the "complex PTSD", and how they apply to traumatized refugees.

1.3 Historical overview

1.3.1 The origin of complex traumatization and trauma-related personality change

The first ideas of complex traumatization are associated with the concept of trauma-related personality change. They originated from the studies of concentration camp prisoners from the World War II. One of the best studies from this time was the Norwegian study of World War II ex-prisoners. - Twelve years after the war, the Norwegian Association of Disabled War Veterans asked for an examination of the former prisoners as it seemed that some were unable to adapt to normal life more than a decade after the World War II[1, 2]. After detailed physical and psychological examinations of ex-prisoners a description of the Concentration Camp Syndrome was put forth [1]. This syndrome comprised what today would have been comorbid symptoms of depression, anxiety, and PTSD. Furthermore, its etiology was related to an organic brain syndrome whereby organic changes were purported to have been caused by disease, starvation, and excessive stress during war captivity [1]. The more remarkable work of the Norwegian Medical Study Group of 1957 was published in 1973[2]. A total of 4,574 surviving Norwegian World War II prisoners were identified in 1966. Their mortality and morbidity rates were compared to those of the Norwegian general population. The

examination revealed much higher mortality incidence rates in the ex-prisoner sample, even though analysis of the ex-prisoner's pre-war files revealed that they were a group representative of the Norwegian adult male population, and thus without any prior risk [2]. Over the next few years, a random sample of 498 individuals, representative of the total war prisoner population, were examined through files from the Norwegian National Insurance Institute and matched with the nearest living control on gender, age, socio economic status, and occupational group. Ex-prisoners and the control sample were compared on a range of background variables including occupational and residence changes, the number and duration of sick leaves, and hospital stays, as well as the character of their diagnoses. The ex-prisoners had significantly higher rates of 13 different diagnoses of physical illness than the controls, in addition to "nervousness and neuroses". Furthermore, almost all diagnoses in ex-prisoners were related to more sick days, longer sick leaves, as well as more frequent and longer hospitalizations than in the controls. For example 30% of the ex-prisoners had more than 365 sick days during the 12 years of study compared to only 8% of the controls. The ex-prisoners also reported elevated rates of frequent job and residence changes, than the control sample. This study further found that for 25.4% of the ex-prisoners the job transition was towards jobs that required lower qualifications and were of a lower income. Importantly, the files indicated that problems related to work and health in the ex-prisoners were not diminishing over time (i.e. the level of the problems remained equally high during the 12 post-war years) [2].Conclusions drawn from this study described *"a group going downhill*" with "*lower working capacity and incomes and fewer opportunities to achieve a sufficient degree of self-realization*" (Eitinger & Strom, 1973, pp. 66) [2]. Furthermore, the authors described the "*increased physical and psychiatric vulnerability"* as being "*permanent"* (Eitinger & Strøm, 1973, pp. 110) [2]. *"The prisoner who was supposedly given limited sentence*

has in fact received a life-long sentence, which reduces his life span, affects the health if not his liberty, and puts a drain on the country's health services. This emphasizes the importance of future prevention of such 'man-made pathology". (Eitinger & Strøm, pp. 110) [2].

Importantly, at the time these findings were published PTSD was not recognized as a disorder. Therefore, the observed psychological sequelae do not correspond to recent diagnoses. However, this study has important implications in modern society due to the representative nature of a population exposed to severe and prolonged trauma of war captivity. It is also assumed, that this study of Norwegian World War II ex-prisoners [2], (and a similar Dutch study cited by Weisæth [3]) set the foundations for research into the area of trauma related *personality change*. The finding of *"permanent increased vulnerability*" to physical and psychiatric problems described in the ex-prisoners sample probably give rise to the idea that psychological trauma can result in *personality change* (i.e. deterioration of pre-trauma personality function). This idea is closely related to the concept of "neuroses". Namely, at the time of the studies of World War II ex-prisoners, "neuroses" were understood as diverse psychological symptoms caused by "character flaws". That is, the concept of "neuroses" is associated with psychiatric vulnerability related to the Freudian concepts of damaged personality development [4]. The excessive prevalence of "nervousness and neuroses" in the ex-prisoners who had *good pre-war function*, thus by definition had to be described as a *change* in the previous personality functioning. At the same time, the documentation of excessive psychiatric morbidity due to war trauma, and not character flaws, de-stigmatizes psychological sequelae in ex-prisoners. Gradually, more humane attitudes towards awarding of war pensions to ex-prisoners emerged [2]. The idea of trauma related *personality change* can be argued to be related

to the understanding of the workings of the human psyche at the time of Eitinger & Strøm. Its perseverance into modern psychiatry however, is associated with much controversy.

1.3.2 **The History of Enduring Personality Change After Catastrophic Experience (EPCACE)**

A diagnosis relating psychological trauma to personality change is for the first time included in the diagnostic nomenclature in the 10th revision of the International Classification of Diseases (ICD-10) under the name Enduring Personality Change After Catastrophic Experience (EPCACE) [5]. EPCACE is classified under *personality disorders* in the ICD-10. Its symptoms are: a hostile or distrustful attitude towards the world, social withdrawal, feelings of emptiness or hopelessness, chronic feeling of 'being on edge', and estrangement. Also, it is specified that the stress must be of such an extreme nature to plausibly account for the observed *personality changes*, irrespective of the person's prior level of functioning [5].

The precise scientific foundation for EPCACE's inclusion in ICD-10 is difficult to trace. However, the official DSM-IV literature review on EPCACE, which was published in 1996, concluded that there are consistent reports of personality change persisting for many years after severe trauma. Recognizable, similar changes are commonly reported consistent with the symptoms of EPCACE. Furthermore, reported patterns of acknowledged personality disorders (PD) in traumatized individuals converge with the pattern of EPCACE. That is, the most frequently reported PD in relation to trauma are schizoid, schizotypal, and avoidant PD (representative of isolation), furthermore paranoid PD (representative of distrust and suspiciousness), and borderline PD (representative of hostility and aggression). However, absence of prospective studies, means that *personality change* occurring in the absence of preexisting personality disturbance is only indicated but not scientifically proven [6]. The review recommended EPCACE for inclusion in DSM-IV as a personality disorder on Axis II [6].

However, EPCACE was not included in the DSM-IV because its etiological pattern deviated from other types of PD[7]. Its etiological component, the trauma, and the relatively rapid onset in adulthood clash with the currently accepted notion of PD as stable maladaptive traits which can be traced back at least to adolescence or early adulthood [7, 8].

1.3.3 **The History of Complex PTSD and DESNOS**

The term Complex PTSD was coined by Judith Herman, who provided detailed clinical descriptions of broad and pervasive trauma-related symptoms (primarily) in adult victims of childhood abuse [9]. Complex PTSD has since become a widely used term for related but slightly different symptom constellations [10]. Judith Herman's Complex PTSD was operationalized and researched during the DSM-IV PTSD trials under the name Disorders of Extreme Stress Not Otherwise Specified (DESNOS). DESNOS was theorized to be related to prolonged *interpersonal* traumatization where the victim is held captive (e.g. political imprisonment, torture and the like), or in the case of a young child, under the psychological control of the perpetrator [9]. It was argued that the captive and the maltreated child were often totally dependent on the perpetrator in terms of basic needs, for example, food, water and human contact. Through controlling of basic needs the perpetrator controls the behavior of the victims – while forcing them to do or endure things that are inconsistent with their own wishes, personal boundaries, and moral beliefs. As a consequence of these gross, prolonged transgressions of personal autonomy, the child's *developing* personality is *shaped,* and the adult victim's *existent* personality is *altered* towards unstable interpersonal patterns, marked self-regulatory deficits, and profound identity confusion [9].

Thus with the emergence of DESNOS two hypotheses about complex traumatization come into being. The first hypothesis is the *personality altering hypothesis,* akin

to the personality change in the EPCACE. It states that extreme interpersonal trauma in adulthood *alters* the previous personality in adult victims towards dysfunctional patterns. The second, new hypothesis, is the *personality shaping hypothesis,* which states that extreme interpersonal trauma in childhood *shapes* the development of the victim's personality towards dysfunctional patterns.

The official literature review preceding the DSM-IV concluded that there were descriptions of *characterological* complex trauma related sequelae, but that trials were needed to provide more systematic evidence of a complex PTSD syndrome [11]. In the DSM-IV PTSD trials DESNOS was operationalized through the Structured Interview for Disorders of Extreme Stress (SIDES) [12]. This 45 item interview schedule assesses six symptom domains that are: 1) alterations in affect and impulses (i.e. affect dysregulation), 2) alterations in memory and consciousness (i.e. dissociation), 3) alterations in self-perception, 4) alterations in interpersonal relationships, 5) somatization, and 6) alterations in systems of meaning. Six symptoms of affect dysregulation, one dissociative symptom, two symptoms of alterations in self-perception, one symptom of alterations in interpersonal relationships, two somatization symptoms, and one symptom of alterations in systems of meaning were required for the presence of DESNOS[12].

Despite the fact that DESNOS could be identified with a high degree of inter-rater reliability and its symptoms were highly inter-correlated [12, 13], it was eventually not included in DSM-IV as a diagnostic category. - Primarily, because most individuals having DESNOS also had PTSD. The conclusion seemed to be that the so called "complex PTSD"/DESNOS is not necessarily a different trauma-related disorder but rather a more severe instance of PTSD. Furthermore, DESNOS was deemed to be too diffuse a syndrome, with varying psychopathological outcomes. It was argued that if such broad psychopathology was

acknowledged as trauma-related it might violate the credibility of the concept itself [13]. Symptoms of DESNOS were included as associated features in the DSM-IV [14], but their mentioning was erased from the DSM-IV-TR [8] 6 years later.

1.4 Empirical findings related to complex traumatization

Despite controversy about the diagnostic status of syndromes of complex traumatization, research on the topic has continued. Box 1 features the search words and inclusion and exclusion criteria of the systematic review.

1. Enduring personality Change After Catastrophic Experience (EPCACE):

Covered databases: PsychInfo, MEDLINE, PILOTS

Search words: enduring personality change, EPCACE

Search last updated: July 2013

Exclusion criteria: theoretical articles and book chapters

Retrieved studies: 5

2. Disorders of Extreme Stress Not Otherwise Specified (DESNOS):

Covered databases: PsychInfo, MEDLINE, PILOTS

Search words: DESNOS, complex PTSD, SIDES

Search last updated: July 2013

Inclusion criteria: empirical studies using Structured Interview for Disorders of Extreme Stress (SIDES) or the Structured Inventory of Disorders of Extreme Stress (SIDES-SR).

Exclusion criteria: book chapters, case studies, dissertations

Retrieved studies: 33

1.4.1 **Empirical support for the EPCACE**

The systematic search of the literature only identified 5 studies of EPCACE (see Box 2). Three of these studies examined conceptual issues surrounding the disorder. They comprised an expert survey [15], a qualitative survey of clinician's understanding of EPCACE [16], and an analysis of discrepancies between the ICD-10's diagnostic guidelines and research criteria for EPCACE [17]. The expert survey and the clinician study found similar conclusions. Specifically, the majority of clinicians embraced the diagnosis and believed that psychological trauma *can* result in personality changes. The most frequently cited EPCACE type trauma were; torture, concentration camp imprisonment, and war. EPCACE had recognizable defining characteristics in the form of hostile and distrustful attitude. Criticisms of EPCACE included that it does not capture many other problems in severely traumatized individuals, e.g. impulsivity, changed self-perception, somatization, survivors guilt, and disturbances in intimacy - and especially that it is difficult to retrospectively assess prior personality functioning.

Only one study systematically examined the prevalence of EPCACE in a large group. Using ICD 10 research criteria it indicated a 6% prevalence of EPCACE in group of 502 compensation seeking Croatian soldiers, and a matched group of 196 non-compensation seeking soldiers. All EPCACE cases were comorbid with PTSD [18]. Finally, a case study of 18 wrongfully convicted individuals from Great Britain who were incarcerated for more than a decade found that 14 had developed EPCACE upon their release from prison [19].

Box 2:
Results of the EPCACE search

Retrieved studies:	**Method:**
▪ Beltran & Silove D. (1999) *[15]*	- Expert survey
▪ Beltran et al. (2008) *[16]*	- Qualitative clinician survey
▪ Beltran et al. (2009) *[17]*	- Examination of diagnostic guidelines & research criteria
▪ Kozarcic-Kovacic & Kocijan – Hercigonja D. (2001) *[18]*	- Prevalence study
▪ Grounds (2004) *[19]*	- Case study

1.4.2 **Empirical support for the DESNOS**

Five studies examining DESNOS were published using the PTSD field trial sample [12, 20-23]. One study developed and validated the Structured Interview for Disorders of Extreme Stress (SIDES) as a means of measuring DESNOS [12]. This measure remains the only standardized operationalization of complex traumatization. Another found high inter-correlation between DESNOS symptom domains of dissociation, somatization, and affect dysregulation [21]. Regularities were observed in the severity of this symptom triad, suggesting that more severe interpersonal traumatization was related to higher symptoms in the three domains [21]. This led to the idea that dissociation, affect dysregulation, and somatization were likely core disturbances in DESNOS. Also in the PTSD field trials, victims of interpersonal trauma, particularly with early onset (age $\leq$ 14 years) had high incidence of all DESNOS domains [22]. This suggests that age of the trauma onset is an important indicator of vulnerability to DESNOS.

Excluding the five PTSD field trial studies, 34 studies examining DESNOS with the SIDES can be currently identified in the databases (see Box 3, p. 28). The studies can be grouped into 18 cross-sectional studies of clinical convenience samples, investigating primarily the prevalence of DESNOS. The clinical studies comprise 9 samples with high frequency of childhood abuse [24-32], 5 studies of war veterans [33-37], 3 studies of traumatized refugees

[38-40], and one study of subjects with PTSD [41]. Furthermore, there are 4 studies in non-clinical samples [42-45], examining the prevalence of DESNOS, and 4 psychometric studies [46-49]. Finally 7 studies classified as "other", have investigated treatment and predictors of DESNOS [50-56].

Studies of clinical samples with high prevalence of childhood abuse have reported DESNOS prevalence rates that range between 20% -50%. These studies include patients with BPD [24, 32], victims of political violence in Northern Ireland [26], patients with substance use disorders [28], somatization disorder [30, 32], forensic patients with PD [31], and three groups of diverse psychiatric patients [25, 27, 29]. High DESNOS prevalence rates have also been reported in war veteran samples that range between 38-58% [33-37, 52-54] (one study with only 10 participants reported a prevalence of 100%). There is further variation among DESNOS prevalence rates in refugee samples with rates between0-66% [38-40]. Finally, the prevalence of DESNOS in representative non-clinical samples has been reported to vary between 2 -13.2% [42, 47].

Among the psychometric studies are two studies that validated the SIDES in German [25] and in Japanese samples [49]. Scoboria and colleagues [46] have made the only proposal of an alternative constellation of DESNOS symptoms. It was based on factor-analytic studies of the SIDES in patients with substance use disorders, and a cross-validation in a high-risk non-clinical sample of incarcerated individuals. SIDES' factor structure did not conform to the 6 proposed DESNOS domains [12]. Instead, a five factorial model was proposed with 20 symptoms identified representing the domains; demoralization, somatic dysregulation, anger dysregulation, self-harm, and altered sexuality. De Jong and colleagues also reported cross-cultural invariance with the SIDES' factor structure across populations in Algeria, Ethiopia and Gaza [47]. Finally,

Zlotnick and colleagues reported that SIDES had good convergence with relevant measures in a sample of victims of childhood sexual abuse [48].

1.4.3 **Empirical studies with refugees**

Only three studies have examined DESNOS in refugee samples [38-40]. Furthermore, two studies of DESNOS in civilian war exposed populations are also interesting in relation to the cross-cultural utility of DESNOS. Namely, De Jong and associates [47] conducted a large scale study of DESNOS in representative adult populations from Gaza (N = 585) Algeria (N = 652), as well as a representative population from refugee camps in Ethiopia (N = 1,200). To date this study has been the largest examination of DESNOS in representative non-clinical groups with an overall sample of 2437 participants. This study utilized the SIDES as a measurement of DESNOS symptoms and reported varying prevalence rates across the three populations (13.2% in Algeria, 5.6% in Gaza, and 2.2% Ethiopia). Another finding of this study was that the factor structure of the SIDES was not stable across the three countries. The authors attribute this inconsistent factor structure to be the result of cultural differences. The SIDES was developed within a strong "Western" framework and the items selected for the measure are arguably based on "western" population's experiences of traumatic events. The "western" wording of symptoms can therefore be argued to reflect universal core symptoms of extreme stress only to some degree. A stable factor structure was however established in Ethiopia, where the sample was large enough to permit a cross-validation by splitting of the sample. Therefore future research is needed to determine the psychometric properties of the scale and its cross-cultural validity.

Morina & Ford [42] conducted a study of DESNOS in 102 Kosovo civilians 6 years post war using a random sampling technique in officially defined representative sections of

the province. The results found that only two individuals had DESNOS. However, prevalence of clinically significant DESNOS symptom domains ranged from 10% – 42%, leading the authors to conclude that more research is needed to examine complex traumatic sequelae in war exposed civilians. Furthermore, the study showed that DESNOS symptoms were associated with poorer psychological functioning, self-evaluations, life-satisfaction, and social support independent of the effects of PTSD.

With regards to refugee samples, Weine and associates [38] examined DESNOS in twenty four Bosnians a year after their resettlement in the USA. They found that none had DESNOS, and they concluded that DESNOS may not apply to victims of genocide. The study was however not designed to test this hypothesis, and methodological limitations, such as the small unrepresentative study group (which received treatment early after their resettlement) do not permit such conclusions. Furthermore, the short time since resettlement could also mean that complex *characterological* adaptations to stress may not have developed at the time of assessment (the definition of PD is persistent inflexible behavioral patterns of a duration of at least 5 years) [8].

Teegen & Schriefe [39] examined DESNOS in 33 treatment seeking torture survivors in Germany. Almost all were male Bosnian survivors of detention camps who had been exposed to severe torture. A total of 94% had been held captive for more than a year. At the time of the assessment a mean of 7.8 years had passed since the torture. The results found that 66% fulfilled criteria for DESNOS. Prevalence of DESNOS symptom domains ranged from 78% to 100%. Notably, 91% had been in treatment for a mean duration of 2.3 years. Limitations of this study were the reliance on self-report measures, and a low participation rate. It is, however, the only study which has investigated the prevalence of complex traumatization in torture survivors

and detention camp prisoners. Furthermore, previously described sequelae in torture survivors (see e.g. DSM-IV reviews [6, 11]) are documented in relation to the DESNOS syndrome. Namely, that DESNOS symptoms in torture survivors persist many years after the exposure to torture despite extensive treatment.

Finally, prevalence of DESNOS, PTSD, and Axis I comorbidity was examined using structured diagnostic interviews in a culturally diverse group of 61 treatment seeking refugees in Norway [40]. About 84% had been resettled in Norway for more than 10 years. Captivity was reported in 52% (torture unknown). A DESNOS prevalence of 16% was reported. Furthermore, the mean number of current Axis I diagnosis in the group was 5.4. The systematic use of structured clinical interviews in this study provides strong support of DESNOS and very broad Axis I comorbid disorders in traumatized refugees. However, the prevalence rates of psychiatric morbidity were somewhat underestimated. Namely, refugees who were not proficient enough in the Norwegian language to participate in the diagnostic interviews were excluded from the study. It is important to note that those unable to learn Norwegian, might however, be the worst afflicted which consequently may have affected the morbidity rates.

Box 3:

Results of the DESNOS search

PTSD field trial studies (N = 5):

	Nationality (other sample characteristics)	N	Investigated
Pelcovitz et al. (1997) [12]	American (PTSD field trail sample)	523	Psychometric properties of the SIDES
Roth et al. (1997) [20]	-	244	Sexual and physical abuse in DESNOS
van der Kolk et al. (1996) [21]	-	520	Inter-correlation between affective dysregulation, dissociation and somatization
van der Kolk et al. (2005) [22]	-	528	DESNOS and early trauma exposure
Newman et al. (1997) [23]	-	82	Thematic resolution in DESNOS

Cross sectional studies in clinical convenience samples:

a) Samples with high prevalence of childhood abuse (N = 9):

	Nationality (other sample characteristics)	N	DESNOS Prevalence
Barnow et al. (2005) [24]	German (BPD patients)	51	31%
*Boroske-Leiner et al. (2008) [25]	German (psychiatric outpatients)	72	34%
Dorahy et al. (2009)[26]	Northern Ireland (victims of political violence)	81	20%
Ford (2008) [27]	American (female psychiatric patients)	38	44%
Ford & Smith (2008) [28]	American (patients with substance use disorders)	231	45%

McLean et al. (2006) [29]	Canadian (treatment seeking women)	70	50%
Spitzer et al. (2009) [30]	German (patients with SoD + control group with MDD)	56	SoD = 36% MDD = 4%
Spitzer et al. (2006) [31]	German (forensic patients with PD)	32	28%
van Dijke et al. (2012) [32]	Dutch (patients with BPD, SoD, BPD+SoD, and controls with anxiety and affective disorders)	472	BPD + SoD 38% BPD 26% SoD 10% Controls 17%
b) Samples of war veterans (N = 5):			
Nemcic-Moro et al. (2011) [33]	Croatian	247	43%
Ford & Kidd (1998) [34]	American	74	57%
Ford (1999) [35]	American	84	58%
Jongedijk et al. (1996) [36]	Dutch	21	38%
Newman et al. (1995) [37]	American	10	100%
c) Samples of refugees (N = 3):			
Weine et al. (1998) [38]	Bosnian	24	0%
Teegen & Vogt (2002) [39]	Primarily Bosnian (detention camp & torture survivors)	33	66%
Teodorescu et al. (2012) [40]	Mixed cultural origin	61	16%
d) Other:			
Zucker et al. (2006) [41]	American (treatment sample with PTSD)	155	16%

Cross-sectional Studies in Non-clinical samples (N = 4):			
Morina & Ford (2008) [42]	Albanian (representative sample)	102	2%
Morina & Stangier (2007) [43]	Albanian (college students)	55	0%
Ford et al. (2006) [44]	American (college women)	345	1%
Teegen & Schriefer (2002) [45]	German (battered women)	71	27%
Psychometric studies (N = 4):			
			Investigated
Scoboria et al. (2008) [46]	American (patients with substance abuse + incarcerated individuals)	231 + 447	factor structure of the SIDES
**de Jong et al. (2005) [47]	Nigerian civilians, Algerian civilians, and Ethiopian refugees (representative samples)	2473	Cross-cultural factor study of the SIDES
Zlotnick et al. (1997) [48]	American (female inpatients - sexual abuse survivors)	74	Convergent validity of the SIDES
Suzuki et al. (2007) [49]	Japanese (other information unavailable, written in Japanese)	-	Validation of the Japanese SIDES
Other Studies (N = 7):			
Dorrepaal et al. (2012)[50]	American (childhood abuse victims)	71	Treatment study
Kaiser et al. (2010) [51]	American (childhood abuse victims)	10	Treatment study
Luterek et al. (2011) [52]	American (treatment seeking war veterans)	208	Predictor study

Simpson et al. (2012) [53]	American (treatment seeking war veterans)	211	Predictor study
Moore et al. (2010) [54]	American (treatment seeking veterans)	203	Predictor study
Ford & Furnier (2007) [55]	American (treatment seeking low-income urban women)	35	Predictor study
McLean & Gallop (2003) [56]	Canadian (patients with BPD and childhood abuse)	65	Predictor study

Note. * also a psychometric study- German validation of the SIDES
** also a prevalence study
BPD = Borderline Personality Disorder
SoD = Somatization Disorder
MDD = Major Depressive Disorder

1.5 Discussion

Despite the clinical utility evidenced in expert and clinical surveys, the overall conclusion is indicative that during its 20 year-long existence, the EPCACE has not been well substantiated by modern research. There are no representative studies of its prevalence, and no clinical studies of its course and treatment. One reason can be that EPCACE was never operationalized in structured diagnostic interviews and questionnaires. A possible reason for this could be that it was overshadowed by the DSM-IV field trials of DESNOS.

With 39 DESNOS studies documenting complex trauma adaptations in a variety of psychiatric populations, it is difficult to ignore that" complex traumatization" exists as a clinical phenomenon, despite it not being an official diagnosis. However the review of DESNOS' empirical foundation over the last 20 years also describes a field which has closed in around

itself. The vast majority of current DESNOS studies are following in the steps of the PTSD field trials - further documenting the high prevalence of DESNOS in psychiatric populations with high frequency of childhood maltreatment. Furthermore, most studies are conducted in small, clinical, convenience samples. Another important criticism of DESNOS literature concerns the limited development, in the field in general. After many years research has yet to extend findings and investigate further issues of extensive comorbidity, and valid measurement of complex traumatization, as reported previously.

Evidence suggests that refugee trauma, the trauma of torture, and imprisonment have not played a particularly salient role in the empirical exploration of complex traumatization. Importantly, the emergence of DESNOS has identified complex traumatization as being largely associated with childhood abuse. However, research on DESNOS has been guided by the PTSD field trial findings, and a sample which did not include any participants with extreme adult trauma (torture survivors, and political prisoners were *unrepresented*, and prevalence of combat related trauma was low) [57].

Furthermore, the PTSD field trial sample may also account for the current close association of DESNOS with Borderline Personality Disorder (BPD). The idea of BPD as a trauma-related disorder associated to childhood abuse was put forward by prominent DESNOS researchers years before the PTSD field trial [58]. Through the PTSD field trail the DESNOS symptoms of affect dysregualtion, dissociation, and somatization got recognized as having a high overlap with symptoms of BPD. However, in failing to include the whole range of extreme traumatization (including refugees, torture, and imprisonment survivors) the PTSD field trial restricted the discovery of complex traumatization symptoms which are potentially different from the BPD-like symptomatology - and could have a different etiology. Further, the

association between DESNOS and BPD did not help the acknowledgement of complex trauma adaptations as a certified diagnosis. After all, there was no need for a new diagnostic category if BPD already encompassed individuals with PD and childhood maltreatment.

What is forgotten in the argument, in which BPD is equated with DESNOS (which is often equated with complex traumatization in general), is that this leaves no diagnostic options for refugees and victims of torture whose complex sequelae have rapid onset in adulthood. Starting with the PTSD field trials, which provided the only ever operationalized concept of complex traumatization, the field has stopped focusing on the personality *changing/altering* trauma hypothesis. That is the pervasive and profound effects of severe prolonged trauma in adulthood have been scientifically neglected, based on the conclusions from a sample unrepresentative of the whole possible range of complex traumatization. The current legacy of DESNOS and research into complex traumatization thus primarily lies in the support for the personality *shaping* hypothesis.

This is despite the fact that refugee trauma has been consistently theoretically related to complex sequelae, and despite the fact that prolonged life-threatening trauma in refugees can easily be the most extreme instance of adult trauma exposure.

Even though there are no studies of EPCACE in refugees, this review has outlined that DESNOS has been investigated and reported in refugee samples within a cross-cultural context. However, there are several limitations associated with these studies, for example, the unrepresentative nature of the samples and a strong focus on prevalence rates rather than psychological outcomes. It is also evident that only one study reported the psychometric properties of the SIDES, and many questions remain unanswered with regards to the cross-cultural validity of this measure. To date, it has not been investigated whether DESNOS

symptoms in refugee samples have a different underlying factor structure than other vulnerable samples, such as, individuals exposed to childhood maltreatment. Research has yet to explore the purported *characterological* nature of complex traumatization by examining the Axis II comorbidity related to the presence of DESNOS in refugees. Finally, the presence of childhood maltreatment in traumatized refugees and its relationship to DESNOS symptomatology has also yet to be examined. It is therefore unknown whether the severity and longevity of refugee trauma independently can induce DESNOS symptoms and symptoms of complex traumatization without prior exposure to childhood maltreatment.

1.5.1 **The social aspects of complex traumatization**

Undoubtedly, the extensiveness and diversity of symptoms of complex traumatization presents problems to the modern science with regards to reliable operationalization and measurement. However, it is often forgotten in the scientific discussion of complex traumatization that existent diagnoses of mental disorders are currently *primarily considered to be social constructs with varying degrees of empirical support* [59, 60]. See e.g. Paris [60] for an overview of challenges related to identification of biological underpinnings of psychiatric diagnoses. The history of traumatization syndromes provides further evidence of this [61]. A much praised analysis of the historical, social, and technological origins of PTSD can be found in Young [61].

Young's research unravels the mechanisms shaping the science of traumatization into process of *social validation* of trauma-related impairment in the *victims*. He argues, that a condition which is per definition related to a specific incident (the trauma) is throughout its history closely related to the awarding of economic and social "compensation". This has been true for the earliest survivors of 1800's train wrecks as well as the American Vietnam veterans,

for whom the PTSD diagnosis was created. At all times however, the victims' creditability was drawn into question by the responsible parties. Therefore, throughout history, time appropriate "scientific" explanations of traumatization were offered, and accepted by the public as validation of impairment in the victims [61]. The same *social* mechanism is evident in the Norwegian studies of World War II ex-prisoners. Namely, the concentration camp syndrome is associated with an underlying brain syndrome – which according to today's science does not exist. But, following the scientific documentation of the great misfortune of the ex-prisoners, which validated their impairment in the eyes of the public, a national change was made towards more "*humane"* practices [2]. Young's historical and social constructionist analysis of PTSD concludes that the currently acknowledged trauma-related disorder- PTSD - may be "unnaturally" limited, and this "illusion" is withheld with the same technology (i.e. psychometric operationalization) which helped validate its existence in the first place [61].

The social constructionist perspective, such as Young's, shapes much of the current thinking about psychiatric diagnoses and scientific development in general [62, 63]. Its basic proposition is that scientific concepts are as much social realities, as they are scientific entities. Change in scientific technology is therefore not only determined by scientific progress but also by social processes (the social conditions behind the creation of a technology and social practices related to its use) [59, 62]. If one accepts this proposition (especially keeping in mind the putative biological evidence for the existence of discrete psychiatric diagnoses [60]) - diagnoses of mental disorders become social tools with several mutually related purposes. - Clinically, they serve to delineate normative and non-normative behavior. Scientifically, they serve as a technology (i.e. scientific concepts with related questionnaires and diagnostic interviews), which guide further exploration and knowledge accumulation. Socially, they serve as the validation of

impairment and as guidelines for action. That is, together, the clinical, scientific, and social properties of psychiatric diagnoses specify who is ill, what kind of impairment they have, and what kind of social action is appropriate as a response. Being partly social constructions (rather than purely objectively defined scientific entities), the development of the clinical, social, and scientific properties of psychiatric diagnoses is not necessarily based on linear consecutive processes. It is rather based on mutually dependent, *cyclical, social*, processes. That is, refinement and changes in one property of a diagnosis influence the other. Consequently, lacking acknowledgement and validation of psychiatric illness in any part of this "scientifically-social" cycle becomes a social problem.

1.5.2 The socio-ideological points of misalignment between PTSD and complex PTSD, and their relationship to refugee trauma

The social problem of complex traumatization is most readily documented by the continuing proposals for acknowledgement of complex traumatization as an independent mental health diagnosis. - As well as the most recent expert survey on complex PTSD, which concluded that clinicians do recognize this category [64]. Furthermore, the resistance against the current diagnostic description of trauma sequelae may be attributed to the large body of evidence indicating the success of PTSD treatments using cognitive and behavioral therapies [65, 66]. Proponents of "complex PTSD" will argue that this evidence does not relate to the *characterological* impairments of complex traumatization. Being conceptualized as personality disorder-alike, "complex PTSD" is thought to be more *chronic* and its symptoms are thought to be more diverse and *extensive* than what is defined by the PTSD diagnosis. Consequently, the expected impairment levels in complex traumatization are thought to be higher than in PTSD and the process of "healing", in "complex PTSD" is purported to be longer and require other methods.

Thus, on the conceptual level, the misalignment between PTSD and "complex PTSD" lays in the *chronicity* and *extensiveness* of the range of purported trauma adaptations. The true social problem of complex traumatization, on the other hand, becomes evident when the offered technologies are unable to treat the observed impairment to a sufficient degree.

How the current lack of *scientific* acknowledgment of the *chronicity* and *extensiveness* of refugee-traumatization acts as a social problem can be illustrated with the case of victims of torture and/or political imprisonment in Western societies. A victim of torture can in the DSM system receive a PTSD diagnosis (also given to an individual who has witnessed a bank robbery), together with a range of comorbid diagnoses. For the treating clinician, this is not very helpful. There are no obvious current guidelines or interventions for the treatment of PTSD "with a hand full of comorbid diagnoses".

Similar problems are evident in the ICD-10. Using the ICD-10 criteria the tortured refugee gets the EPCACE diagnosis. But this diagnosis lacks scientific underpinning. It has not been scientifically documented. - In social constructionist terms, it therefore has no validity in the eyes of the public. Also, in absence of its scientific documentation and associated technologies, (including treatment possibilities and prognosis) the public does not know what actions are appropriate towards individuals with the EPCACE diagnosis. When the aviated "healing" of the torture survivor, who has been offered the best available treatment (often based on knowledge of PTSD) extends the norms of societal expectations (also often based on knowledge of PTSD), and he is not able to support himself financially, the societal institutions often do not know what to do. So the refugee is involved in well-meaning but overwhelming processes of trying new possibilities for, treatment, work, and social inclusion. This practice of searching out possibilities is rather costly in the modern welfare states. Unfortunately, it might

not be helpful to the tortured refugee either. His continuing participation in promoting inclusion is not entirely voluntary, as it is often a prerequisite for the securing of economic support from the society. Importantly, the clinically observed symptoms of complex traumatization which include pervasive problems with self-regulation and distrust towards others imply that this process could be aggravating the refugee's trauma-related symptoms. The securing of economic existence by participating in activities that are outside ones control and difficult to manage emotionally, does not help the healing, regaining of personal autonomy and a sense of self in an individual whose boundaries have been grossly transgressed during torture, imprisonment, and persecution. In this respect, the history of the Norwegian ex-prisoners from World War II teaches us that research is essential, in order for the society to implement more humane and socially relevant practices. But the question is also, whether wider acknowledgment of complex traumatization as a socially relevant issue is not a moral imperative, as much as a scientific endeavor?

1.5.3 **Current diagnostic developments**

As of May 2013 the American official nomenclature for mental disorders has been extended with a fifth revision - the DSM-5 [67]. Complex PTSD was once again proposed for inclusion in the DSM (a more precise outline of the proposal cannot be identified in the currently published literature). A highly critical review of complex PTSD was published from the DSM-5's Task Force for Trauma Related Disorders [10]. The main conclusions cited serious problems with reliable operationalization and measurement of complex PTSD. Complex PTSD was not clearly differentiated from PTSD, BPD, and major depressive disorder (MDD), while at the same time it included many unspecific symptoms from existing psychiatric diagnoses. Therefore, the validity of the construct did not live up to current standards, and its inclusion in DSM-V was not

supported [10]. The continuing debate of complex PTSD amongst American proponents and opponents can be followed in the special issue regarding complex PTSD in the Journal of Traumatic Stress (vol. 25, 2012). The editor of this leading journal in the field has commented that PTSD would have never been included as a diagnostic category in DSM-III had it been held to the standards that complex PTSD is being held to today [68].

In the upcoming revisions of the ICD-11 under the World Health Organization (WHO), the committee on trauma-related disorders proposed the un-researched EPCACE to be replaced by Complex PTSD (CPTSD) [69]. A narrower PTSD diagnosis and a "sibling" CPTSD diagnosis have been proposed [69, 70]. Symptoms of CPTSD for ICD-11 were selected on the basis of the commonly reported symptoms from a recent expert study on complex PTSD and available DESNOS studies [70]. The proposition of CPTSD in ICD-11 cites 1) *fulfilled criteria for current PTSD* with co-occurring self-regulatory problems in the domains of: 2) *affective regulation*, 3) *negative self-concept*, 4) and *interpersonal problems* [70]. Core impairments related to interpersonal problems in CPTSD are defined as estrangement and avoidance in an effort to better differentiate CPTSD from BPD. Finally, the trauma type criterion is not restricted. It is thus stated that CPTSD is most likely to occur after prolonged trauma, but that self-regulatory problems characteristic of CPTSD may be observed in vulnerable individuals following less severe trauma as well (Ibid).

The proposed CPTSD has not yet officially been operationalized. That is, no structured interviews and questionnaires have been devised for the purpose of assessing CPTSD. One study supporting the distinction between the proposed PTSD and CPTSD in ICD-11 has been published [70]. The results are encouraging. However, the importance of proper operationalization of the CPTSD in ICD-11 cannot be stressed enough. Especially, related to the

WHO's role of a world spanning organization, the cross-cultural reliability of CPTSD measures is strongly desired, as well as inclusion of refugees and torture survivors in the field trials of the new diagnosis. Furthermore, several questions remain unclear. For example, what does the proposed "sibling" relationship of CPTSD with PTSD really mean? That is, what is the relationship of the proposed CPTSD to be with personality disorders in ICD-11. – More specifically, how is the unmet need for the acknowledgment of the *chronicity* and *extensiveness* of complex trauma adaptations in refugees and other victims of extreme trauma going to be met with the CPTSD?

1.6 Conclusion

The history of complex traumatization shows repeated attempts to create a diagnosis which can capture more *chronic* and *extensive* psychiatric symptoms than those defined by PTSD. Throughout its history, concepts of complex traumatization have been related to personality dysfunction, and two specific hypotheses. One is related to the proposition that extreme interpersonal traumatization *shapes* the personality of victims of childhood abuse in a pathological direction. The other hypothesis proposes that extreme interpersonal trauma *alters* the previous personality of adult victims towards pathological patterns. The majority of research on complex traumatization has been made in relation to the personality *shaping* hypothesis. Probably because of competing diagnostic proposals in the DSM and the ICD, the personality *altering* hypothesis has been scientifically neglected. Also, in terms of modern science the personality *altering* hypothesis has roots in an outdated understanding of the human psyche. Importantly, this long-standing proposition is today difficult to validate to a sufficient degree, as the afflicted individuals usually cannot be identified and studied before the occurrence of trauma.

The s*ocial* problem of appropriate diagnostic categorization of complex traumatization related to *extreme* trauma in *adulthood* remains. Despite the problems of misfit with established diagnostic concepts, a social analysis of complex traumatization points to a moral imperative related to the recognition of *chronic* and *extensive* psychological sequelae in victims of e.g. torture and political imprisonment. The main issues are currently large problems in assessment and treatment of refugees, because there is no meaningful way to organize the diversity and chronicity of symptoms which are sometimes observed in this group. The observed diversity, extensiveness, and chronicity do not fit well established notions of the more transient clinical syndromes such as PTSD. On the other hand, the etiology of symptoms in adult victims of extreme traumatization does not fit with the more chronic and pervasive personality disorders either. Thus to be accommodated as a diagnosis, a change has to be made in the existent thinking about the overall categorization and mechanisms behind the psychiatric diagnoses. This is not a quickly achieved state, neither socially nor scientifically. The *social* acknowledgment of *extensive* psychological impairment in for example victims of torture and political imprisonment thus awaits the proper technologies. The reliable measurement and operationalization of complex traumatic sequelae in traumatized refugees are a scientifically neglected but a much needed effort.

2 Chapter 2: Aims and methodology of the studies in the thesis

Chapter one indicated that complex traumatization in refugees is generally a neglected area of research. Only 4 prior studies of DESNOS in refugees existed. Many central questions about the nature of complex traumatization in refugees remain. These gaps in research knowledge include; what is the underlying structure of complex PTSD symptoms in refugees (i.e. what are the most central symptoms)? Is complex PTSD symptomatology in refugees more similar to Axis I or Axis II disorders? Does complex PTSD exist in refugees who do not have a history of childhood maltreatment? Are some complex PTSD symptoms more stable across different cultures? Finally, can complex traumatization (or its domains) be reliably assessed and screened for, to allow for use in everyday clinical practice with traumatized refugees? Furthermore, the integrative review in chapter 1 indicated that operationalization is an especially pertinent challenge to the understanding and utility of complex PTSD. That is, *systematic* scientific documentation and clinical use are dependent on the ability of complex PTSD to be reliably measured in traumatized refugees. This chapter provides an overview of the methodology which is applied in the thesis.

2.1 The overall purpose of the thesis

The general purpose of this thesis is to further validate the concept of complex traumatization in the clinical and research practice with traumatized refugees by developing and testing its measurement (i.e. operationalization) and assessment. The thesis comprises two studies, the DESNOS, and the HoNOS study. The two studies supplement each other by examining complex traumatization in refugees on different levels. The DESNOS study comprises a clinical *convenience* sample of Bosnian refugees from 6 Danish rehabilitation clinics for traumatized refugees, while the HoNOS study comprises a group of *consecutive* refugee

patients from one of the Danish rehabilitation clinics for refugees. The HoNOS study therefore, builds upon the DESNOS by including a more representative treatment seeking sample. However, it assesses complex traumatization in refugees on a general level, with a global psychiatric measure. While the DESNOS study comprises a smaller refugee sample, the participants have been assessed in detail for DESNOS and psychiatric morbidity. Due to the challenges related to measurement of refugee trauma (*specified under 2.3.3 in more detail*), thorough examination of multifaceted psychiatric concepts in representative groups of traumatized refugees is currently difficult to accomplish.

Both the DESNOS and the HoNOS study have clinical and psychometric objectives. With regards to the clinical objectives, the aims were to *describe* the character of symptoms of DESNOS and complex traumatization in refugees. With regards to the psychometric objectives the aims were to explore to what extent the observed symptoms can be adequately assessed, measured, and *operationalized*. The ultimate aim, therefore, was to develop a measure of complex PTSD for use in the clinical practice with traumatized refugees.

2.2 The aims of the DESNOS study

The DESNOS study was planned as an explorative study. Specifically, related to clinical objectives in the thesis the aims of the DESNOS study were to:

1. Describe the *character* of DESNOS in refugees by examining its comorbidity with acknowledged Axis I and Axis II disorders.

2. Examine if childhood maltreatment is a necessary prerequisite for the development of DESNOS and Axis II pathology in traumatized refugees.

Related to the psychometric objective the aims of the DESNOS study were to:

1. Analyze the underlying structure of DESNOS in traumatized refugees.

2. Investigate to what degree DESNOS domains can be reliably measured in traumatized refugees (including universality of symptoms).

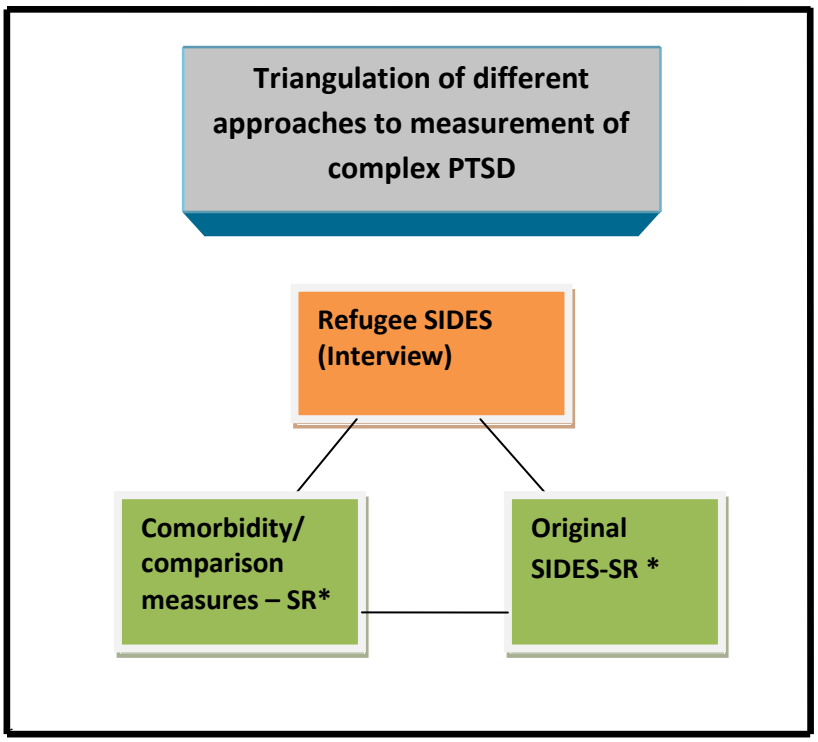
Despite its limitations, DESNOS was the starting point in the exploration of complex traumatization in refugees. It was considered a "good enough" starting point, because it is the only operationalized concept of complex traumatization, and studies had already shown that DESNOS symptoms are endorsed by traumatized refugees.

2.3 Design of the DESNOS study

2.3.1 **The overall design**

The design of the DESNOS study comprised the following elements: a refugee adapted version of the SIDES, devised to test the universality of DESNOS symptoms in refugees. It was to be compared with the original SIDES administered as a self-report measure (SIDES-SR) [71]. Also, comparison/comorbidity measures were included for each of the DESNOS' symptom domains to test whether they can be reliably assessed. Axis I and Axis II comorbidity in the refugee group was studied with a global psychiatric measure. Finally, exposure to war trauma as well as childhood maltreatment was assessed in the study. The assessment procedure consisted of two parts, a structured diagnostic interview with the refugee adapted SIDES, and a self-report questionnaire which included the original SIDES-SR, comorbidity/comparison measures, and measures of trauma exposure. Figure 1 gives a general overview of the design.

Figure1. Overview of the study design



SR = self-report

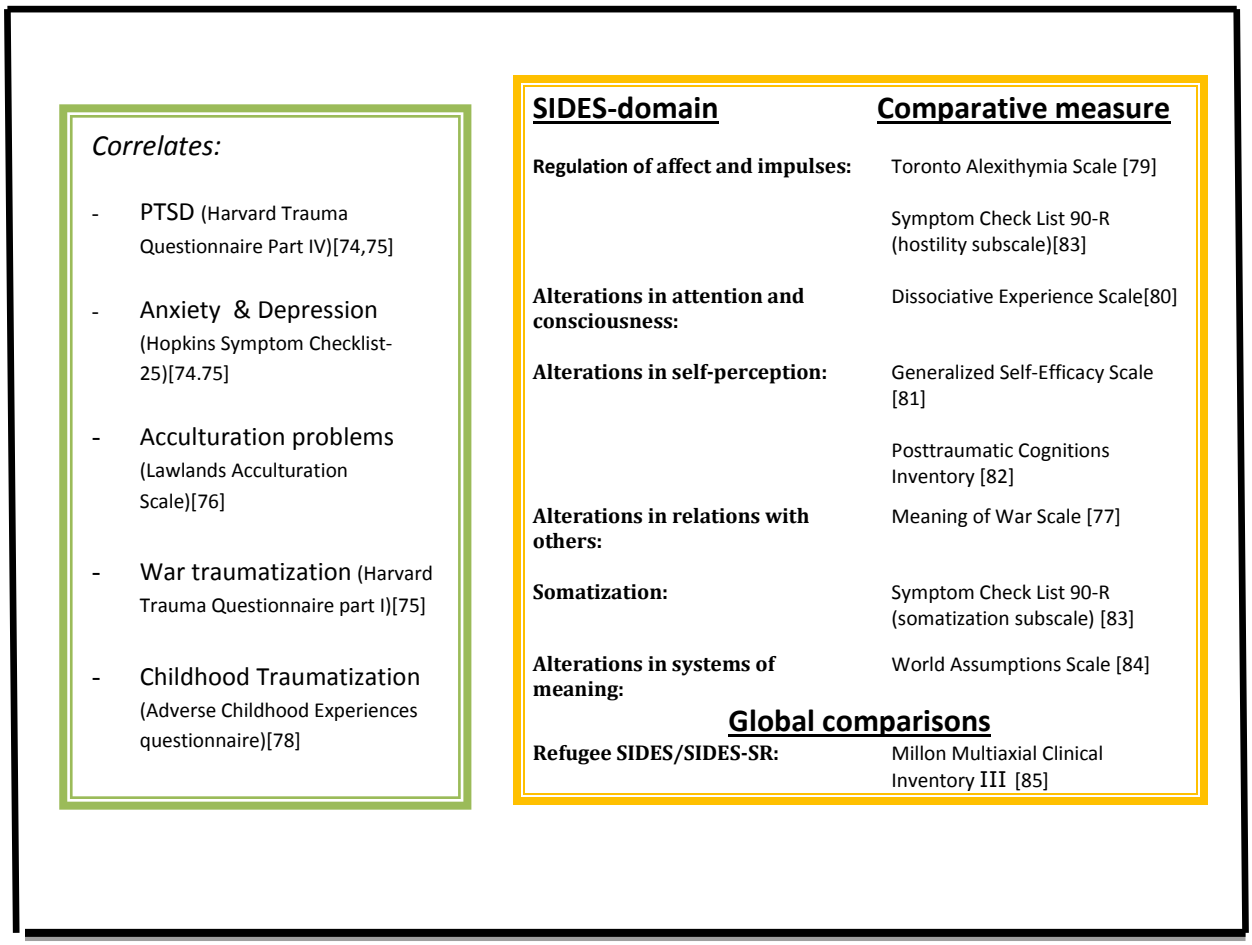
2.3.2 **Sample size**

The most central problem related to complex traumatization in refugees is arguably its underlying symptom structure in this group. Therefore, using a broad syndrome like DESNOS may identify a refugee-specific syndrome of complex traumatization. However, to be able to answer questions about the structure of DESNOS in refugees the study had to include enough participants to allow for a factor analytic study of the SIDES. By the lowest rule of thumb 225 participants are required for a factor analytic study of a 45-item measure like the SIDES [72]. This was a desirable aim, but it was at the early stages of the research design recognized that a clinical group of traumatized refugees of the required size would be difficult to obtain. If the requirements for factor analysis could not be met, the DESNOS study was also designed to explore the psychometric properties related to assessment of DESNOS' separate symptom domains which could be explored in smaller groups.

2.3.3 **Rationale behind the use of comparison measures**

A general challenge related to the study of psychiatric symptoms in refugees has to be mentioned in relation to the planned design with comparison measures. Namely, very few psychiatric measures have established psychometric properties in refugee groups. The only existent validated measures are self-report measures of PTSD, anxiety, and depression. Furthermore, a very few of these measures have established properties of sensitivity and specificity with diagnostic "golden" standards [73].This means that measurement validity is a general challenge in the research of refugee trauma. The comparison measures in the present design, although they can seem excessive, are necessary to ensure the construct validity of the examined phenomena. Namely, the triangulation of measures in the design allows for comparisons of prevalence, convergence, and measurement precision for each DESNOS domain across different modes of measurement. Hence if at least two measures assessing the same concept indicate comparable results, the construct in question has been captured as intended. Figure 2 describes the applied comparison and comorbidity measures.

Figure 2. Measures in the Design



2.3.4 **Rationale behind the choice of the research population**

Another challenge to the validity of measurement of psychiatric concepts in refugees relates to the cultural heterogeneity of the research population. In studies involving several refugee groups translations of western measures have to be made for each refugee group. An important factor to consider when using measures that are translated into different languages is that the quality of the translation may vary from one refugee sample to another. Importantly, some psychiatric symptoms from western measures do not have universal expressions across different cultures, and some psychiatric symptoms may not be universal at all. However, the effects of cultural heterogeneity, inadequate translations and non-universal symptoms on the

performance of the psychiatric measures are traditionally not explored in factor analysis. Factor analysis is a method for testing the overall structure of an underlying variable (i.e. a psychiatric construct)[86]. If a culturally heterogeneous refugee sample is to be applied in a factor analytic study, it therefore, would be difficult to identify if the abovementioned problems related to cross-cultural measurement were present, and if they were primarily responsible for the factor structure of the identified construct.

In order to minimize the problems of cross-cultural measurement, the strategy for the present study was to sample refugees from Bosnia and Herzegovina only. Furthermore, examining refugees from Bosnia & Herzegovina makes exploration of personality disorder symptoms in refugees manageable. Personality disorders are by definition maladaptive behaviors which are culturally inappropriate [8] . The Bosnians coming from a European country have a similar cultural background of their neighbor countries in Eastern and Southern Europe. This makes exploration of personality disorder symptoms with established measures more straight forward. Finally, the clinical interviews were conducted in Bosnian by the author and trained psychology and medicine students who also resettled in Denmark as refugees from Bosnia and Herzegovina. Thus, personality disorder symptoms on the SIDES were assessed by individuals who have the same cultural background as the study participants. This is the most direct way of avoiding problems related to the culturally relative definition of personality disorder.

2.4 Procedures in the DESNOS study

2.4.1 **Participants**

Participants were patients from Danish specialized clinics for treatment and rehabilitation of traumatized refugees in the towns of Ålborg, Aarhus, Horsens, Holsetbro, Viborg, Vejle, Odense, Haderslev, and Sønderborg (covering the referral areas of Jutland and Feunen). Because of logistic challenges, other parts of Denmark were not covered. A clinical population was sampled because the purpose of the thesis was to improve the utility of complex PTSD in the clinical practice with traumatized refugees.

Refugees who spoke the Bosnian/Croatian/Serbian language and were in treatment or on a waiting list for treatment at one of the clinics were eligible participants. Furthermore, they had to be assessed by the clinic to be without acute suicide risk. Those who volunteered to participate were sent the questionnaire of self-report measures seven days before they were scheduled to appear for a clinical interview that was being held at the clinic. Interviews were also conducted at the participant's homes if they wished so. All participants received written information about the study in Danish and Bosnian/Serbian/Croatian and a phone number to contact the researcher if they had further questions or they changed their mind about participation. Participants provided written informed consent at the time of the clinical interview. Their travelling expenses were covered.

2.4.2 **Ethics**

The study was presented to the Danish National Committee on Health Research Ethics. The committee deemed that the study did not require the approval, because it is not a treatment study, and no biological material was collected. Thus the clinical interview was not deemed to have the character of an "intervention". The study was approved by the Danish Data

Protection Agency and was conducted according to the ethical guidelines of the involved clinics and ethical principles governing the work of Nordic psychologists [87].

2.4.3 **Measures and Translation**

As a general rule, measures which already existed in Bosnian were applied. Only the Harvard Trauma Questionnaire, the Hopkins Symptoms Checklist, the Lowlands Acculturation Scale and the Meaning of War Scale had known psychometric properties in Bosnian refugees [74-77]. The SIDES, SIDES-SR, Millon Mulitiaxial Clinical Inventory-III, Toronto Alexithymia Scale, Symptoms Checklist 90-R (hostility and somatization subscales), Generalized Self-Efficacy Scale, Posttraumatic Cognitions Inventory, and the Adverse Childhood Experiences Questionnaire were translated and back translated into Bosnian by the first author and Bosnian born psychologists or psychiatrists working in Denmark. Two individuals worked on each translation. Inconsistencies between the translation and back translation were determined through the consensus of the two translators. The measures were translated based on the principle that they should convey the *meaning* of the translated items in everyday language, rather than literal translations with high grammatical resemblance to the original items. The translated measures were subjected to further review by two Bosnian high school teachers to validate understanding and use of everyday language. Finally a pilot study involving 10 volunteers from the organization of Bosnian detention camp survivors in Odense was undertaken to test the utility of the translated self-report measures and adapt items which were difficult to understand. The time required to fill out the questionnaire varied between 50 and 90 minutes in the pilot study. All the translated measures have been standardized in other populations. More details about the measures and their psychometric properties can be found in the original validation articles (for references see Figure 2, pp. 47).

2.4.4 **Adaptation of the SIDES interview**

Adaptation of the SIDES interview was made to reflect instances where the author and the supervisor agreed that universal symptoms of extreme stress existed but could have specific cultural or refugee related expressions. These were item no. 33 *("When you have problems (arguments or conflicts) with other people, how do you work them out?"*) and item no. 45 *("Do you have the same moral beliefs that you grew up with?"*). Here, the original questions were retained but behavioral anchors were supplemented for item no. 33 to reflect high levels of resignation related to problem solving in some refugees. In the same way, behavioral anchors were supplemented for item no. 45 to include instances of drastically *strengthened* religious beliefs after trauma (i.e. becoming more religious).

Three items pertaining to sexual dysfunction were thought to be culturally inappropriate (item no. 12 *"making efforts not to think about sex*", item no. 16 "*talking about sex more than you want to*", and item no. 18 "*sexual activities that put you in danger*"). They were removed from the interview and replaced by a general question about sexual dysfunction *("Have you noticed any problems or negative changes related to your sexual activities?"*). The remaining questions about modulation of sexual involvement were retained as in the original SIDES.

Finally, items were added on an explorative basis, to ask about symptoms which could be expressions of complex traumatization in refugees. These were questions about 1) prolonged periods of emotional numbing (i.e. unable to feel anything), 2) alternative forms of behavioral disinhibition when upset (disinhibited smoking, eating or drinking, unable to eat, make oneself vomit, pulling own hair out, and other), and 3) "separation anxiety" from spouse or children (excessive controlling and checking of whereabouts of family members because of fear that something bad might happen to them).

2.4.5 **Training of the students**

Bosnian born medicine and psychology students were recruited to support with the assessment. They were paid by the hour and had their travelling hours and expenses covered. Most students were trained as one group. They received 5 days of training with the author as the instructor. They learned to assess symptoms of PTSD, generalized anxiety, and depression, in order to be able to differentiate them from DESNOS symptoms. Training for the refugee adapted SIDES interview was conducted through role play. Each student took part in a number of interviews with the instructor playing the role of the patient. The interviews were simultaneously rated by the other students. Results of the rating and interview technique were afterwards discussed in the group. Finally, the instructor accompanied the students to one or two of their first interviews. Only two students eventually went on to make their own interviews. A self-compiled booklet of definitions of PTSD, depression, anxiety, and DESNOS symptoms, akin to the SCAN glossary [88] was available to all raters. The two students made about 40% of the interviews. The rest were conducted by the author, who had training in using structured diagnostic interviews on Axis I with the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) [88] and on Axis II with the Structured Clinical Interview for DSM-IV Axis II Disorders (SCID-II) [89].

2.4.6 **Changes in the procedure**

Several sample recruitment problems arose at the early stages of the study with regards to finding willing volunteers. Furthermore, many participants who initially agreed to participate did not show up for the clinical interviews or did not return the questionnaires. Feedback from clinicians found that some individuals wished to fill out the questionnaire whilst others only

wanted to participate in the interview stage. Finally, a large proportion of the volunteers had completed their treatment by the time of assessment.

In order to compensate these recruitment and data collection problems, the procedure was changed to allow participants to opt for interview based assessment or to complete the self-report measures. Those who wished to participate in both stages of the assessment were still able to do so. To have a basis for analyzing the data from the clinical interviews a short (4 page) questionnaire assessing symptoms of PTSD, anxiety, depression, as well as war trauma and childhood maltreatment was completed by the participants at the end of the SIDES interview. Those who only wished to complete the self-report measures were sent the questionnaire with a pre-paid, pre-addressed return envelope. Individuals who had finished treatment were also included in the study. Clinics agreed to take in participants for short stabilizing treatment should any of the already treated individuals be unstable or very distraught by the assessment procedure. No such instance occurred.

Finally, to improve the participation rate, an inducement was offered by giving vouchers for a department store (value 100 Danish krouns). One clinic was selected to use the voucher incentive and they were in the mail to all eligible participants together with the general information about the study written in Danish and Bosnian. However, this did not seem to have the desired effect. The rate of participation did not improve in comparison to another clinic whereby data had been collected beforehand without the voucher. Some patients also called the research team (the number was printed on the information material in case the patients wanted more information about the study) explaining that they did not feel well enough to participate and wanted to return the voucher. This was despite the information in the letter explaining that

the voucher was theirs to keep whether they decided to participate in the study or not. The use of the voucher incentive was therefore removed when data collection began at the next clinic.

2.4.7 **Analytical Plan**

The final sample included 146 individuals. Of these, only 86 had participated in both assessment parts (the self-report and the clinical interview). Additionally 33 individuals filled out only the self- report measures (making the total number of filled out SIDES-SR and the comparison measures 119). Finally, 24 individuals participated only in the clinical interview, making the total number of conducted Refugee SIDES interviews 100. As it was not possible to do factor analysis on this sample, the DESNOS studies examined the convergence and classification agreement across different measures.

2.5 Background of the HoNOS study

The HoNOS study came about through a collaboration with the Clinic for PTSD and Transcultural Psychiatry in Århus (CPTP), which also provided patients for the DESNOS study. The clinic wanted to evaluate and assess the effectiveness of their treatment, and had undertaken data collection based on routine measurement of patients in the clinic. One measure in particular was well suited for the examination of complex traumatization in refugees. – The Health of Nation Outcome Scales (HoNOS) – an observer rated scale of global psychiatric impairment [90].

2.6 The aims of the HoNOS study

In addition to the overall aim of the thesis (measurement and description of complex PTSD in treatment seeking refugees) the purpose of the HoNOS study was to supplement the DESNOS study. Specifically, this study aimed to address the limitations regarding the unrepresentative nature of the sample and *small sample size* in the DESNOS study,

by including a larger group of refugees. This permitted more *rigorous psychometric testing* in a more representative sample. Like the DESNOS study, the HoNOS study also had overlapping psychometric and clinical objectives.

The clinical objective was:

1. To explore the viability of the proposed diversity of psychiatric problems in a *representative* clinical group of traumatized refugees.

The psychometric objectives were to:

1. Test the underlying structure of symptoms of general psychiatric impairment in a large, representative group of traumatized refugees.

2. Furthermore, to explore whether a psychometrically sound measure of the diverse psychiatric impairment in traumatized refugees could be developed for use in the research and the clinical practice.

2.7 Design and rationale of the HoNOS study

The HoNOS was thought to be a useful component in the study of complex PTSD because it is a global psychiatric measure which is broad enough to encompass the diverse symptoms of complex traumatization in refugees. Impairments parallel to most DESNOS domains are rated on the HoNOS. Specifically, HoNOS ratings of aggressive and self-injurious behavior cover aspects of *affect dysregulation* in DESNOS. Ratings for depressed mood cover DESNOS' *alterations in self-perception and systems of meaning*. Physical illness problems rated on the HoNOS can encompass DESNOS' *somatization*. Interpersonal problems on the HoNOS capture *alterations in relations to others* in DESNOS. Furthermore the HoNOS encompasses

ratings of comorbidity which are important in capturing aspects of a diffuse "syndrome" which cannot be rated otherwise.

An additional quality of the HoNOS was that it is a widely used psychiatric measure [91]. This made it possible to compare the proposed diverse profile of psychiatric impairment in traumatized refugees with the impairment profile of 10.500 Danish psychiatric patients with acknowledged psychiatric diagnoses. Importantly, the HoNOS study sample was collected over 3 years. It comprised 448 individuals, and was thus large enough to allow for more rigorous psychometric exploration of the allegedly extensive and diverse trauma-related symptoms in treatment seeking refugees.

2.8 Procedures in the HoNOS study

2.8.1 Participants and procedures

The participants in the HoNOS study were 448 consecutive refugee patients at CPTP and its three departments (Århus, Horsens and Randers). The refugee patients originated from 22 different countries (more details can be found in articles 3 & 4). The HoNOS study was conducted as a naturalistic study in the clinics. Consecutive patients starting and finishing treatment during a 3 year period were assessed by the treating psychologists with routine measures, used for treatment purposes. The Psychiatric Centre North Zealand (PCNZ), had introduced and validated the HoNOS for use in Denmark. Collaboration with PCNZ was instigated, which enabled the comparison of refugees' global impairment with that of other Danish psychiatric patients. The HoNOS data for patients at PCNZ were also collected as a part of routine monitoring for treatment purposes.

2.8.2 **Ethics**

The study was approved by the Århus University Hospital, Risskov under which CPTP belongs. Procedures for the storage of data at the clinic were approved by the Danish Data Protection Agency. Because the data were routinely collected for treatment purposes, and analyzed retrospectively, informed consent form the patients was not asked.

2.8.3 **Measures**

The HoNOS did not require translation into the respective languages as it is an observer-rated measure. A validated Danish version of the HoNOS was applied in the study [92]. All psychologists at CPTP had received some training and supervision in the use of the HoNOS, but the amount of training and supervision was not systematically controlled.

2.8.4 **Analytical plan**

Two articles on the HoNOS data were developed. The first HoNOS article had clinical aims. It described and compared the norms on the HoNOS for the refugee patients and other psychiatric patients. The second article was a psychometric study on the refugee HoNOS sample. Considering the large cultural diversity of the refugee patient group the most widely used psychometric strategy (factor analysis) was not thought to be appropriate. Instead, Rasch analysis was identified as a (relatively) new psychometric method, which could possibly circumvent issues traditionally related to cross-cultural measurement. Importantly, as the HoNOS assessment for refugees was obtained at pre-treatment as well as at post-treatment, the HoNOS could be validated in the pre-treatment data, and cross validated in the post-treatment data. This would give additional information as to HoNOS' utility as a monitoring tool in the group of treatment seeking refugees.

3 Chapter 3: Articles from the DESNOS study

3.1 Article 1: Personality Dysfunction and Complex Posttraumatic Stress Disorder Among Chronically Traumatized Bosnian Refugees

Sabina Palić, MSc Psychology[1]

and

Ask Elklit, Professor of Clinical Psychology[1]

[1] National Centre for Psychotraumatology, Institute of Psychology, University of Southern Denmark, Odense, Denmark.

Abstract

A proposal for the inclusion of complex Posttraumatic Stress Disorder (CPTSD) in the upcoming ICD-11 has been put forward. Using self-report we investigated the resemblance between Disorders of Extreme Stress Not Otherwise Specified (DESNOS) and both Axis I and II syndromes among 116 treatment-seeking, Bosnian refugees. In this sample the prevalence of DESNOS overlapped to a large degree with the prevalence of Schizotypal and Paranoid Personality Disorders (PD). There was however also a large prevalence of Axis I syndromes in the group. Thus, DESNOS in refugees can be categorized as an Axis I or II disorder depending on the chronicity and severity of functional impairment. DESNOS and PD-alike states were even observed among refugees with no history of childhood maltreatment. No large differences were observed between DESNOS and PD regarding gender. The symptom constellation of CPTSD in the ICD-11 is partially supported. However, CPTSD might resemble PD to a considerable degree.

Keywords: personality disorder, refugees, Bosnia and Herzegovina, DESNOS, complex PTSD, C-PTSD

Introduction

Traumatized refugees in Western countries often present with diverse symptoms of mental disorder, which do not all feature in the current diagnosis of Posttraumatic Stress Disorder (PTSD) [1]. The level of traumatization among refugees is often extreme encompassing experiences of persecution, genocide, political imprisonment, torture, beatings, rape and sexual exploitation, frequent bombings, losing loved ones, losing all possessions, hunger, and disease. For many refugees, exposure to trauma is yearlong and consists of multiple traumas. Historically, there have been two attempts to create diagnoses that cover the pervasive effects of such extreme life stressors. The International Classification of Diseases (ICD-10) features the diagnostic criteria for Enduring Personality Change After Catastrophic Experience (EPCACE), which encompasses chronically hostile or suspicious attitudes, social isolation, estrangement, hopelessness, and chronic alertness [2]. As part of the PTSD field trials for DSM-IV, Complex PTSD[3] was studied under the name Disorders of Extreme Stress Not Otherwise Specified (DESNOS) [4]. DESNOS consists of a large number of diverse symptoms covering the following six domains of dysfunction: affect and impulses, attention and consciousness (i.e. dissociation), self-perception, relations with others, somatization, and, systems of meaning. In terms of demarcation from other syndromes, there exists some overlap between symptoms of DESNOS and depression [5]. Furthermore, many symptoms of DESNOS overlap with those of Axis II disorders. There is an especially large overlap between DESNOS and Borderline Personality Disorder (BPD) [5, 6]. Moreover, persistent symptoms of distorted self-perception, social isolation, and suspiciousness overlap with symptoms of schizoid, schizotypal, paranoid, and avoidant personality disorders from the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) [7].

There are problems regarding the demarcation and assessment of DESNOS, which create obstacles when it comes to the use of DESNOS as a diagnostic category [5]. Also, while the diagnosis of EPCACE seems to be used for traumatized refugees [8], it has remained almost completely un-researched since its conception. Despite problems with diagnostic demarcation, clinicians and researchers have insisted on the meaningfulness of the complex PTSD as a trauma-related disorder, one which is qualitatively different from PTSD [9]. Furthermore, a proposal for the inclusion of complex PTSD (CPTSD) in the revisions of the ICD-11 diagnostic nomenclature has *again* been put forward [10]. Based on available DESNOS literature and an expert survey on Complex PTSD it has been suggested that CPTSD in ICD-11 should be comprised of current PTSD with disturbances in affect regulation, negative self-concept, and interpersonal problems [11]. Former DESNOS domains, somatization and alterations in systems of meaning have been excluded from the proposed diagnosis of CPTSD whereas estrangement and avoidance of interpersonal relationships have been given more prominence in order to differentiate CPTSD from BPD. Prolonged dissociation is proposed to be included under affective dysregulation [11]. Being deducted from DESNOS the CPTSD proposal still resembles DESNOS, but it has also been brought closer to the EPCACE which has suspiciousness, social isolation, and estrangement at its core. The first evidence supporting the proposed distinction between CPTSD and PTSD has been published [11]. However, it is also proposed that CPTSD is to have a "sibling" relationship to PTSD in ICD-11, and that CPTSD is more malleable to psychotherapeutic interventions than personality disorders (PD) [10]. Studies have yet to back up this claim. Meanwhile, on the conceptual level, the emphasis on functional impairment within the diagnostic criteria of CPTSD coupled with affective dysregulation and interpersonal problems resemble Axis II type pathology. Indeed, newer insights indicate that the strongest

indicators of PD are persistent interpersonal problems and functional impairment, and *not* the stability of specific PD symptoms [12].

Besides the symptom overlap there is also overlap in etiology between complex PTSD syndromes and PD. This is indicated by high incidences of Adverse Childhood Experiences (ACE) in both PD [13-15], DESNOS [16], as well as the proposed CPTSD [11]. Of all PD, BPD has consistently been found to show the strongest unique associations with different forms of ACE [13, 15]. Schizotypal Personality Disorder (SPD), although also considered to be a schizophrenia spectrum disorder, is also associated with traumatic exposure in both childhood and adulthood [17-19]. Importantly, on a conceptual level the SPD and BPD have the largest symptom overlap with DESNOS and the proposed CPTSD.

Complex PTSD/DESNOS has seldom been systematically studied in refugees. Only three smaller studies exist [20-22]. Until now, proposals and revisions of complex PTSD syndromes have been made without empirical evidence for this group. Considering the repeated prolonged life-threatening experiences, torture, and political imprisonment, the refugee group comprises individuals with some of the most extreme adult trauma exposure. Because of symptom and etiological resemblance with BPD, the concept of complex PTSD is however currently closely related to the trauma of childhood maltreatment and Axis II pathology. Little is known about whether complex PTSD sequalea and Axis II pathology apply to extreme trauma experienced only in adulthood.

Although we know from previous studies that DESNOS can be present among traumatized refugees, it has not yet been established whether PD-like symptoms can be present among traumatized refugees when the presence of ACE has been excluded. Furthermore, the

comorbidity of complex PTSD and Axis II pathology in refuges has never been studied. A large overlap between DESNOS and Axis II syndromes in traumatized refugees will imply that complex traumatization is indeed Axis II alike in the group. The possible overlap of complex traumatization with Axis II syndromes in refugees is important to examine with regards to the proposed "sibling" relationship of the CPTSD and PTSD in the upcoming ICD-11. The study examines following questions:

(1) To what degree do BPD and SPD resemble DESNOS and DESNOS domains proposed to comprise CPTSD when they are assessed in traumatized refugees?

(2) Is the presence of ACE necessary for the development of complex traumatization and PD? That is, could DESNOS, CPTSD or even PD apply to traumatized refugees even when there is no presence of ACE?

(3) Furthermore, are DESNOS and Axis II pathology equally prevalent in men and women with refugee trauma?

Complex traumatization will be examined using the concept of DESNOS as it is the broadest of the "complex PTSD" syndromes; it comprises all of the problem areas that feature within the proposed ICD-11 diagnosis of CPTSD (direct measures of CPTSD have not yet been developed). The study will assess the correlation and convergence between Structured Inventory for Disorders of Extreme Stress (SIDES-SR), which measures DESNOS, and the Million Multiaxial Clinical Inventory III. - A measure of PD that also comprises scales for a number of Axis I disorders. Given that DESNOS reflects PD in refugees, it is hypothesized that the SIDES-SR and its subscales will demonstrate the highest positive correlations with the MCMI-III Axis II scales, particularly the borderline and schizotypal scales. This hypothesis

concerns all of the SIDES-SR subscales apart from somatization, which is measured on Axis I. Also, if DESNOS captures Axis II pathology in refugees there should be a high overlap in the estimated prevalence of complex PTSD, BPD and SPD. The study will furthermore explore whether DESNOS and PD are especially related to ACE and gender in traumatized refugees. Finally, given that there are no validated measures for PD and DESNOS for refugees, if predictable convergence is found between the above mentioned measures, then it is also likely that the measures will have performed as intended in relation to the present refugee population.

Method

Participants and procedures

Participants were 116 Bosnian refugees who had fled to Denmark from the 1992-1995 war in Bosnia-Herzegovina. Participants came from a European, secularized society, which had pre-war living and educational standards comparable to many of its European neighbors (because PD is per definition a culturally relative concept [7], the European origin of the participants makes exploration of personality dysfunction with western measures straight forward in this group). The United Nations has documented the extent of the atrocities committed during the war; the Bosnian, mainly Muslim, population was exposed to genocide and ethnic cleansing, imprisonment in detention camps, mass murder, torture, systematic rape, and forced deportation [23].

Participants were recruited from 6 out of 10 possible rehabilitation centers for traumatized refugees in Denmark. All Bosnian-speaking patients were considered to be potential participants. Exclusion criteria included the presence of severe alcohol or drug addiction, a primary diagnosis of psychotic disorder, and acute suicidal threat. All participants provided

written consent to participate in the study. The study was conducted in accordance with the Ethical Principles for Nordic Psychologists [24], as well as the ethical guidelines of the rehabilitation centers.

Recruitment of participants ran from May, 2010 to May, 2011. In centers which reported approximate participation rates they ranged from 13 - 39%. At the time of assessment, 57% of the participants had completed treatment, 28% were currently in treatment, and 15% were on a waitlist. Participants were between 30 and 67 years of age (M = 46.5; SD = 8.1). The average length of stay in Denmark was 16.1 years (SD 3.0; Range 4-20 years). 53% of the participants were female. 72% had at least 12 years of formal education. Participants' experiences of severe war trauma are categorized as follows: loss of a close family member (90%), torture (72%), beating (53%), imprisonment in detention camps (51%), and, rape and other sexual assault (33%). 72% of the participants were outside of the labor market. The present study was conducted using participants recruited for a larger research project regarding the assessment of complex PTSD among traumatized refugees. Participants who filled- out all of the self-report measures were included in the present study (80% of the original sample).

Measures

The *Self-Report Inventory of Disorders of Extreme Stress* (SIDES-SR) was used to determine presence of DESNOS and morbidity on its symptom domains [25, 26]. SIDES-SR is a 45-item, self- report questionnaire developed on the basis of the SIDES interview from the PTSD trials for DSM-IV [4]. Participants were asked to indicate, on a scale from 0 to 3 (0 = no symptoms, 3 = severe symptoms), the presence and severity of symptoms during the last month. The measure showed good internal consistency. Cronbach's alpha coefficients for the SIDES-SR and its subscales are presented in Table 1.

The *Millon Multiaxial Clinical Inventory- III* (MCMI-III) is a 179-item, self-report measure of Axis I and II pathology. Most of the scales reflect DSM-IV disorders [27]. The measure comprises 14 Axis II personality pattern scales, and 10 Axis I clinical syndrome scales (see Table 2). Cronbach's alpha coefficients for the MCMI-III scales were in the range of those reported for the original American version as well as other validated translations [28, 29]. They are presented in Table 2. Prevalence of pathology on the MCMI-III was estimated using Danish clinical norms [28]. Base rate (BR) scores on the MCMI-III range from 0 to 115. Higher scores indicate higher symptom levels. BR $\geq$ 75 indicates the presence of sub-clinical PD. BR $\geq$ 85 indicates a probable PD diagnosis. BR $\geq$ 75 on an Axis I scales indicate a probable Axis I diagnosis. Profiles that did not fulfill the MCMI-III validity criteria were excluded. All of the questionnaires were translated and back translated into Bosnian. Inconsistencies between translation and back translation were determined by consensus between the translators.

Adverse Childhood Experiences (ACE) was assessed using 5 dichotomous (yes/no) questions derived from a previous ACE study [30]. The questions covered emotional, physical and sexual maltreatment, as well as physical neglect and the witnessing of violence between parents before the age of 18 years. Each ACE question was supplemented by 2 questions that addressed the age at which the specific trauma started and the age at which it ended. In accordance with the DESNOS paradigm[16], the ACE trauma types that occurred at the age of 14 years or earlier were considered to be indicative of ACE. The ACE trauma types that occurred at a later age were considered to be ACE negative.

Data analyses

Statistical analyses were performed using SPSS for Windows 19.0 (SPSS Inc.). Overall, 16.9% of the data were missing, which is an acceptable level for imputing missing values [31]. Little's MCAR test indicated that data were missing completely at random. Data on all standardized measures were imputed using the Expectation Maximation Algorithm in SPSS. Due to the restricted sample size and the relatively large number of repeated comparisons, both unadjusted p-values and post-hoc Benjamini-Hochberg adjustments for multiple testing [32] are reported.

Results

Correlation between the SIDES-SR and the MCMI-III

Fourteen participants had invalid MCMI-III profiles. There was missing information for 9 individuals on the ACE variable. Even without adjustments for multiple testing ($p < .05$ maintained in all tests), there were no differences between participants who had and hadn't completed treatment regarding scores on the SIDES-SR, SIDES-SR subscales or any of the 24 MCMI-III scales. Therefore, all participants were treated as one group. Table 3 shows the correlations between the SIDES-SR, SIDES-SR subscales, and MCMI-III scales. Many of the scales correlated strongly, positively and significantly ($p < .0001$) with each other (the significance level was adjusted for multiple testing; 168 repeated tests). The SIDES-SR correlated strongly and positively with a large number of the Axis I and II scales on the MCMI-III. The strongest positive correlation was found between SIDES-SR and the schizotypal scale on Axis II ($r = .74$). The SIDES-SR also correlated strongly with the borderline scale ($r = .72$) and the following Axis I scales: thought disorder ($r = 73$), somatoform ($r = .72$), dysthymia ($r = .71$), and, major depression ($r = .71$). Notably, the correlation between SIDES-SR and PTSD was also

strong and positive, but somewhat lower (r = .64). In terms of divergent validity, negative correlations were found between all of the SIDES-SR subscales and the histrionic, narcissistic, and compulsive MCMI-III scales.

Prevalence of DESNOS and Axis I and II pathology

Table 1 depicts the prevalence of DESNOS and DESNOS symptom domains (including those that feature in the proposed CPTSD diagnosis for ICD-11). In the total sample, the prevalence of full-scale DESNOS was 34% (M = 51.1, SD = 22.1). Furthermore, 23% of the total sample fulfilled the criteria for five of the DESNOS symptom clusters. Table 2 presents percentages of clinical and subclinical syndromes on the MCMI-III scales. According to the cut-off for PD (BR ≥ 85), there is a prevalence of 20-40% of internalizing (avoidant, depressive, self-defeating) personality patterns in the total sample. In contrast, the prevalence of externalizing personality patterns such as histrionic, narcissistic, and antisocial is 0-4%. On the severe personality pathology scales, the paranoid personality patterns had the highest prevalence (23%) in the total sample. This is followed by schizotypal personality patterns (20%). Pathological (BR ≥ 85) borderline personality patterns (5%) were much more rare in the group. When mutual comorbidity on the three scales for severe personality disorder was excluded, 32% of the total sample scored above the cut-off (BR ≥ 85) on either the Schizotypal, Borderline or the Paranoid scale (because of mutual comorbidity the prevalence of severe personality disorder sums up to 48% in Table 2). However, all cases who were positive on the Borderline scale were also positive for Schizotypal PD. Table 2 indicates that Axis I syndromes were more prevalent in the refugee group than Axis II syndromes. The most prevalent Axis I disorders included PTSD, anxiety, dysthymia, major depression, and somatoform disorder. All were much more prevalent than DESNOS.

The relationship of ACE and Gender to PD and DESNOS

29% of the refugees in the present sample had experienced at least 1 ACE at the age of 14 years or earlier. As expected, refugees with ACE (M = 56.7, SD = 16.7) scored significantly higher on the SIDES-SR ((114) = 2.03, $p < .04$) compared to refugees without ACE (M = 48.8, SD = 23.7). However, no significant differences were found between refugees with and without ACE regarding the fulfillment of DESNOS criteria. As regards to the MCMI-III, refugees with ACE scored significantly higher on the depressive personality pattern (Axis II) scale than refugees without ACE ($t(100) = 3.31$, $p < .001$). Refugees with ACE also scored significantly higher than refugees without ACE on the borderline ($t(100) = 2.55$, $p < .02$), and bipolar/manic (Axis I) scales ($t(100) = 2.03$, $p < .04$). No other significant differences were observed between refugees with and without ACE on the MCMI-III. Table 2 presents descriptive statistics (means and standard deviations) for the MCMI-III base rate scores acquired by refugees with and without ACE. No differences were observed between refugees with and without ACE regarding the prevalence of those who met a probable a PD diagnosis (BR > 85) on the MCMI-III. Finally, after correcting for repeated testing, the only difference that remained statistically significant was the difference found between refugees with and without ACE regarding scores on the depressive personality scale. None of the prevalence comparisons remained significant.

The descriptive statistics presented in Table 4 indicate no large gender differences in relation to acquired levels of PD and DESNOS in the present sample. The only significant gender differences were found in relation to the compulsive personality pattern, where women scored significantly higher than men ($t(100) = 3.0$, $p = .003$), and for passive-aggressive personality patterns, where men scored significantly higher than women ($t(100) = 2.2$, $p = 0.03$). Finally, men demonstrated a higher prevalence of passive-aggressive personality pathology compared to

women ($X^2(1) = 4.38$, $p = 0.04$). After correcting for repeated testing, only the scores with $p \leq 0.003$ remained statistically significant (i.e. women had higher scores on the compulsive personality pattern compared to men).

Discussion

As predicted, the strongest positive correlations were found between the SIDES-SR and the schizotypal and borderline scales on the MCMI-III. Contrary to expectations, a clear pattern of stronger correlations was, however, not found between the SIDES-SR and the Axis II scales on the MCMI-III when compared to the Axis I scales. However, the strong, positive correlations of the SIDES-SR with *dysthymia, major depression, anxiety,* and *PTSD* are not unexpected as they probably reflect known comorbidities of DESNOS [5]. The positive associations found between the SIDES-SR, the SIDES-SR subscales and the *somatoform scale* were in agreement with the predictions of this study. The strong positive correlation found between the *alterations in attention and consciousness scale* (i.e. dissociation) and the *thought disorder scale* on the MCMI-III is probably found because the *thought disorder* scale describes strange perceptual and attentional experiences, which appear to define psychotic symptoms just as well as they do dissociative symptoms. Indeed, the behavioral expression of dissociative symptoms is often confused with psychotic symptoms [33]. It is therefore important to employ measures that are able to discriminate between these symptoms accurately. Given that individuals with a primary diagnosis of psychotic disorder are excluded from the rehabilitation centers for refugees in Denmark, the MCMI-III and the SIDES-SR were most likely tapping into dissociation symptoms in the present sample. The overall pattern of SIDES-SR's correlation with Axis II and Axis I disorders in general supports the notion that aspects of trauma-related symptoms were captured predictably in the refugee population, and that the SIDES-SR and

MCMI-III measures performed as they were supposed to. The notion that complex PTSD was successfully measured in the present population is further supported by the presence of divergent validity between the SIDES-SR and the *histrionic*, *narcissistic* and *compulsive scales*. These disorders differ from DESNOS in terms of symptom content. Moreover, a prior study used a narcissistic scale to establish divergent validity from the SIDES [34].

Convergence of morbidity rates

The prevalence estimates on the MCMI-III indicate extremely high and rates of comorbidity of Axis I and II disorders among refugees in the present sample. DESNOS in the present refugees can be said to resemble Axis II pathology. Namely, the finding that 32% of the treatment-seeking, traumatized refugees score above the cut-off for at least one of the three severe personality disorders on the MCMI-III is comparable to the 34% prevalence of DESNOS. Thus, 82.4% of refugees who fulfilled the criteria for DESNOS also qualified for either paranoid, schizotypal, or borderline PD on the MCMI-III. While prevalence of other PD in the group is even higher, the comparison of DESNOS prevalence with that of the severe PD makes the most sense because of the already hypothesized symptom overlap. However, the prevalence estimate of around 30% for PD-like states in the present refugee population is at the same time quite conservative. The 57% of refugees who fulfilled the criteria for at least 5 of the DESNOS symptom domains and the 50-70% who reported subclinical symptoms on the schizoid, dependent, avoidant, depressive, and self-defeating PD scales on the MCMI-III (BR $\geq$ 75), could probably qualify for a DSM-IV diagnosis of Personality Disorder Not Otherwise Specified (PD NOS). Indeed, it has been found that psychiatric patients with ACE who also are suspected of having complex PTSD often fulfill the criteria for PD NOS rather than discrete PD diagnoses [35]. Thus, DESNOS in the present refugees can probably best be characterized as PD NOS with

many comorbidities on Axis I. Indeed, PD's often co-occur with disorders such as dysthymia, major depression, anxiety, and PTSD [36]. However, the longevity of PD symptoms and the related functional impairment also needs to be studied in traumatized refugees in order to determine whether complex traumatization in the group should primarily be considered Axis I or Axis II alike. As already mentioned, the strongest indicators of PD over the time are functional impairment and persistent interpersonal problems [12].

It should also be kept in mind that the refugees in the present sample were assessed using self-report measures. Future studies need, therefore, to corroborate the prevalence of different PD syndromes among traumatized refugees through the use of diagnostic interviews. However, the rates of morbidity found on the two measures demonstrate convergence and strengthen the validity of the present conclusions.

Implications of the present findings for the proposed CPTSD

Contrary to the proposals for the upcoming ICD-11, in which CPTSD is conceptualized as being discernible from PD [11], the present findings indicate that complex traumatization is just as strongly associated with PD among traumatized, treatment-seeking refugees as it is with Axis I syndromes. Importantly, DESNOS domains of affective dysregulation, interpersonal problems, and self-perception which are a part of CPTSD have strong positive correlations with the Schizotypal and Borderline scales in traumatized refugees. Furthermore, as proposed in the CPTSD, there is also a large prevalence of pathological paranoid personality patterns. Thus, the present findings support the proposed CPTSD diagnosis for ICD-11 with regards to their emphasis on avoidance and estrangement in interpersonal relationships. That is, the prevalence of both schizotypal and paranoid personality patterns was found to be almost four times higher than that of borderline personality patterns in the present sample (also

Borderline patterns never occurred without Schizotypal patterns). However, the higher prevalence of schizotypal and paranoid symptoms observed in the present sample may not apply to all populations with complex traumatization. A study by Allen, Coyne, & Huntoon indicates the opposite pattern; a twofold prevalence of borderline over schizotypal personality patterns and a fivefold prevalence of borderline over paranoid personality patterns were found among women with a history of severe childhood traumatization [37]. This prevalence pattern matches the well-established relationship between development of BPD and ACE [13, 15]. The higher prevalence of estrangement and suspiciousness in the traumatized refugees is in the meantime also in line with previous research, which indicates a possible unique association between schizotypal symptoms and exposure to trauma in adulthood [18], as well as high rates of comorbidity between PTSD and SPD [36]. Early childhood maltreatment is, on the other hand, known to have a profound impact on the consolidation of personality [3]. The effects of severe interpersonal trauma in adulthood - although devastating - cannot be expected to have the same effects on victims who have undergone a normative personality development. The underlying process of extreme traumatization in adulthood is thus probably different from that of childhood. Hence, the related symptom expressions are not unlikely to be different as well. Possible differences in pathological personality patterns found between refugees without ACE and individuals with childhood traumatization need further examination in order to determine whether they indicate the presence of different syndromes or subtypes of CPTSD.

Turning to the proposed narrowing of symptoms in the CPTSD, the exclusion of the DESNOS cluster known as *alterations in systems of meaning* makes sense in light of the present findings, because *alterations in systems of meaning* correlated most strongly with dysthymia and major depression on the MCMI-III. Such symptoms are common among

psychiatric patients and are, therefore, unlikely to represent the core dysfunctions in CPTSD. However, the same was true regarding the DESNOS cluster known as *alterations in self-perception,* which is defined as "negative self-concept" in the proposed CPTSD diagnosis for ICD-11. Thus, future operationalization of the negative self-concept in CPTSD needs to be given careful consideration in order to differentiate it from depression and dysthymia. Importantly, problems with negative self-image of a more severe nature than that associated with depression were found among 30% of the refugees in this sample. They came in the form of pathological schizoid, depressive, and dependent Axis II personality patterns on the MCMI-III. Also in line with the CPTSD, problems with affective regulation were observed among the refugees in this sample; 50% endorsed this domain on the SIDES-SR and 22% had subclinical borderline patterns on the MCMI-III (the paranoid and schizoid patterns were however more severe and prevalent). It also appears that somatization symptoms express themselves rather frequently among traumatized, treatment-seeking refugees. They also correlate highly with other clusters of proposed CPTSD impairment. Thus, in light of these findings, the role of somatization in CPTSD has to be further examined. Finally, in agreement with the newest proposals for CPTSD, PTSD is likely to co-occur with complex traumatization and DESNOS in traumatized refugees.

The impact of ACE and Gender on DESNOS and PD

It is difficult to determine the precise impact that ACE has had on DESNOS and PD in the present sample due to the small sample size (only 34 refugees reported a history of ACE) and the use of repeated testing. Overall, the higher scores found among refugees with ACE on the SIDES-SR as well as the depressive and borderline scales on the MCMI-III make sense in light of previous findings regarding the close relationship between DESNOS, BPD, and ACE [13, 16, 17]. The most interesting findings associated with the present study are that full-scale DESNOS

and dysfunctional personality patterns were present in severely traumatized refugees without ACE, and that severe war traumatization in adulthood appears to have had largely the same impact on PD symptoms in both men and women. These findings support the proposed CPTSD diagnosis for ICD-11, which acknowledges the complex relationship between genetic and environmental vulnerability factors in shaping the symptoms of complex PTSD [11]. This allows for the designation of complex PTSD in relation to less severe trauma in particularly vulnerable individuals as well as to severely traumatized individuals with a presumably healthy pre-trauma personality.

Understanding CPTSD as PD-like?

The current study indicates that symptoms of complex traumatization in refugees on their face value have the same expression as PD symptoms (in particular paranoid and schizotypal). At the same time it is also indicted that the etiology of PD symptoms in traumatized refugees probably differs from the currently accepted etiology for PD, in which an interplay of biological vulnerability and ACE is often indicated [19,38]. In this case, the proposal that the new diagnosis of CPTSD should be more malleable to treatment compared to PDs could be appropriate. However, future studies are needed to determine whether the functional and interpersonal impairments as well as the chronicity and malleability of PD-like symptoms found among traumatized refugees without ACE correspond to those found in PD patients with more established etiology. Disputes regarding the conditions that warranted the development of PD-like impairment among the refugees in the present sample may be raised due to: (1) the 16-year time lapse since exposure to war trauma; (2) the diversity and type of self-reported symptoms; and, (3) the presence of functional impairment in terms of exclusion from the labor market despite very high levels of education. Finally, a CPTSD diagnosis in the upcoming ICD-11

makes little sense unless it is proven that the functional impairment and constellation of symptoms associated with CPTSD are different enough from PTSD to warrant a different prognosis and treatment. In light of the present findings, we believe that these indications may well come in the form of CPTSD demonstrating a greater resemblance to Axis II than Axis I pathology.

Limitations

The present study examined a clinical convenience sample of Bosnian refugees only. The participation rate was low. Considering the high education level reported among participants and the extensive assessments in the larger study, it is likely that only the highest functioning Bosnian patients from the Danish rehabilitation centers participated in the present study. Thus, a study that had examined a more representative sample of clinical refugee populations in the West may have found an even higher prevalence of Axis I and II morbidity among traumatized refugees. However, as there are no previous studies that have attempted to describe the full extent of Axis I and II morbidity among refugees with complex traumatization, the present study is the first of its kind to indicate the extent of such problems in this population. MCMI-III is not a diagnostic tool and it has not been validated in relation to Bosnian norms. Instead, Danish clinical norms were used to estimate the prevalence of PD in the present study. However, since the refugees in this sample had been living in Denmark for a long time and were European, the use of Danish norms may not have been entirely inappropriate. Given that only self-report measures were used in this study, future studies should corroborate the present findings through the use of diagnostic interviews. In the meantime, the use of two self-report measures that largely tap into the same constructs serves to strengthen the conclusions that can be drawn from the present findings. Traumatized populations tend only to be assessed after

traumatization has occurred, hence the pre-morbid personalities of traumatized individuals cannot be evaluated. It is therefore difficult to directly investigate whether traumatization in adulthood functions as a risk factor for the development of personality dysfunction. Finally, the strong positive correlations found between the SIDES-SR and MCMI-III subscales can partly be attributed to the structural similarity of these two measures. Furthermore, a number of the MCMI-III scales are known to demonstrate high inter-correlations because same items are included in multiple scales, but are weighted differently when included in disparate scales. Therefore, the correlations between the SIDES-SR and different MCMI-III scales are probably more similar in strength than they would have been if other measures of PD had been employed.

Conclusions

Very high and complex patterns of comorbidity are indicated in the present sample of "resource strong" traumatized refugees. The diverse comorbidity found among traumatized refugees in the present study renders the American DSM-V, which does not acknowledge complex PTSD[39] limited in terms of usefulness in guiding the treatment of traumatized refugees. In light of the lessons learned regarding very broad conceptualizations such as DESNOS, the simplification of the proposed CPTSD diagnosis in the upcoming ICD-11 is desirable and partly supported by the present study. However, a more precise relationship of the proposed diagnosis of CPTSD to PTSD has to be formulated. In future studies, the chronicity and the level of the functional impairment related to CPTSD will be good indicators to test its possible similarity with PD. PD-alike symptoms appear to be common among refugees with complex traumatization. The development of sound diagnoses and measures of complex trauma-related symptoms in refugees is greatly needed in both research and clinical practice. Longitudinal studies of complex PTSD and PD-like symptoms in refugee populations are also needed.

3.1.1 Table 1

Cronbach's alpha coefficients for the SIDES-SR scales plus % prevalence of DESNOS, DESNOS symptom domains, and total number of endorsed DESNOS domains in the ACE positive, the war trauma only, and the total group.

		Prevalence		
Characteristic	α	ACE positive (n = 34)	War trauma (n= 82)	Total (n =116)
Cluster/ Scale				
Regulation of affect and impulses*	.86	53%	48%	49%
Attention and consciousness*	.78	77%	77%	77%
Self-perception*	.77	77%	59%	64%
Relations with others*	.72	91%	79%	83%
Somatization	.78	88%	66%	72%
Systems of meaning	.80	79%	71%	73%
DESNOS	.94	38%	32%	34%
No. of endorsed DESNOS clusters				
0		0%	11%	8%
1		6%	6%	7%
2		6%	7%	6%
3		12%	9%	9%
4		9%	15%	12%
5		29%	21%	23%
6		38%	32%	34%

Note. SIDES-SR = Self-report Inventory of Disorders of Extreme Stress; DESNOS = Disorders of Extreme Stress; ACE = Adverse Childhood Experience, * symptom domains proposed to be included in the CPTSD

3.1.2 Table 2

Cronbach's alpha coefficients and descriptive statistics for the MCMI-III base rate scores acquired by the ACE positive, the war trauma only, and the total groups.

Personality patterns and clinical syndromes		ACE positive (n = 31)				War trauma (n = 71)				Total (n=102)			
	α	M	SD	% ≥ 75	% ≥ 85	M	SD	% ≥ 75	% ≥ 85	M	SD	% ≥ 75	% ≥ 85
Axis II: Clinical Personality Patterns													
Schizoid	.72	76.9	16.6	61	36	79.1	17.0	68	41	78.5	16.9	66	39
Avoidant	.83	79.3	12.9	68	36	73.0	22.3	66	31	74.9	20.0	67	32
Depressive	.80	80.6	10.5	77	39	70.1	21.5	45	23	73.3	19.4	55	28
Dependent	.77	76.4	20.9	71	32	77.2	19.1	70	30	76.9	19.6	71	30
Histrionic	.77	22.6	16.5	0	0	26.4	20.8	1	0	25.2	19.6	1	0
Narcissistic	.63	37.9	20.9	3	3	43.8	22.2	6	4	41.9	21.9	5	4
Antisocial	.74	43.8	19.9	3	3	38.8	21.4	0	0	40.3	20.9	1	1
Aggressive	.77	56.7	13.8	7	0	54.0	17.8	4	0	54.8	16.7	5	0
Compulsive	.57	42.8	17.1	0	0	44.9	16.9	1	0	44.3	16.9	1	0
Passive-aggressive	.76	74.1	14.2	52	19	70.4	20.5	54	20	71.5	18.8	53	20
Self-defeating	.84	73.1	16.1	65	23	68.2	21.0	45	20	69.7	19.7	51	21
Severe personality patterns													
Schizotypal	.86	72.1	11.9	39	16	67.2	21.1	37	21	68.7	18.9	37	20
Borderline	.78	66.5	11.8	29	3	58.5	19.5	18	6	60.9	17.8	22	5
Paranoid	.80	79.4	15.1	58	26	73.4	18.5	39	21	75.3	17.6	45	23
Axis I: Clinical syndromes													
Anxiety	.80	98.4	9.5	100	90	93.9	18.7	93	79	95.3	16.5	95	82
Somatoform	.80	86.1	15.4	68	48	80.1	19.5	54	39	81.9	18.5	58	42
Bipolar-manic	.66	61.8	15.1	16	7	54.2	18.5	1	1	56.5	17.8	6	3
Dysthymia	.85	84.0	17.1	81	45	77.9	24.4	72	42	79.8	22.5	75	43
Alcohol dependence	.68	59.6	13.6	13	0	56.4	17.8	9	3	57.4	16.6	10	2
Drug dependence	.67	37.4	21.4	3	0	32.5	22.6	0	0	34.0	22.3	1	0
Posttraumatic stress	.86	84.7	11.5	81	45	79.8	17.1	69	39	81.3	15.7	73	41
Severe Syndromes													
Thought disorder	.82	68.9	12.6	19	7	65.8	16.8	21	7	66.8	15.6	21	7
Major depression	.86	85.8	13.7	77	61	80.4	19.6	65	47	82.1	18.1	67	51
Delusional disorders	.75	61.9	21.9	13	7	57.8	23.9	16	9	59.1	23.3	15	8

Note. SIDES-SR = Self-report Inventory of Disorders of Extreme Stress; DESNOS = Disorders of Extreme Stress; ACE = Adverse Childhood Experience

3.1.3 Table 3

Correlations between the MCMI-III scales and both the SIDES-SR and its subscales (N = 102)

	SIDES-SR	Regulation of affect and impulses	Attention and Consciousness	Self-perception	Interpersonal-relations	Somatization	Systems of meaning
Axis II Clinical Personality Patterns							
Schizoid	.60**	.52**	.50**	.50**	.57**	.32**	.62**
Avoidant	.69**	.60**	.52**	.61**	.61**	.40**	.70**
Depressive	.63**	.49**	.57**	.58**	.54**	.40**	.66**
Dependent	.54**	.41**	.48**	.47**	.48**	.36**	.60**
Histrionic	-.54**	-.53**	-.38**	-.49**	-.39**	-.28**	-.52**
Narcissistic	-.20	-.14	-.09	-.24*	-.11	-.16	-.29**
Antisocial	.47**	.42**	.34**	.40**	.55**	.17	.46**
Sadistic	.40**	.41**	.26**	.33**	.47**	.16	.33**
Compulsive	-.36**	-.35**	-.25*	-.35**	-.38**	-.10	-.33**
Negativistic	.61**	.57**	.48**	.53**	.60**	.27**	.59**
Masochistic	.69**	.62**	.54**	.62**	.62**	.35**	.68**
Severe Personality Pathology							
Schizotypal	**.74****	.63**	.65**	**.64****	**.68****	.45**	.70**
Borderline	.72**	**.65****	.61**	.62**	.64**	.39**	.69**
Paranoid	.46**	.42**	.36**	.37**	.48**	.26**	.40**
Axis I Clinical Syndromes							
Anxiety	.69**	.61**	.63**	.56**	.58**	.42**	.66**
Somatoform	.72**	.57**	.65**	.60**	.60**	**.54****	.67**
Bipolar-manic	.43**	.37**	.44**	.29**	.46**	.27**	.33**
Dysthymia	.71**	.59**	.56**	**.66****	.63**	.40**	**.74****
Alcohol dependence	.56**	.54**	.43**	.48**	.53**	.28**	.52**
Drug dependence	.24*	.21*	.18	.20*	.34**	.05	.24*
PTSD	.64**	.56**	.58**	.51**	.52**	.39**	.63**
Severe Syndromes							
Thought Disorder	.73**	.58**	**.71****	.60**	.66**	.46**	.72**
Major Depression	.71**	.58**	.62**	.62**	.62**	.40**	.72**
Delusional Disorder	.49**	.44**	.40**	.38**	.46**	.29**	.44**

Note. Highest correlations between the SIDES-SR and MCMI-III scales is highlighted in bold.
* $p < .05$, ** $p < .0001$
SIDES-SR = Self-report Inventory of Disorders of Extreme Stress; ACE = Adverse Childhood Experience

3.1.4 Table 4

Descriptive Statistics for Males and Females for Scores on Axis II scales on the Millon Multiaxial Clinical Inventory III and the Structured Inventory of Disorders of Extreme Stress (SIDES-SR).

Personality patterns and clinical syndromes	Female (n = 52)		Male (n = 50)	
	M	SD	M	SD
Axis II: Clinical Personality Patterns				
Schizoid	77.9	15.6	79.1	18.3
Avoidant	75.1	18.0	74.7	22.2
Depressive	70.8	19.2	75.8	19.4
Dependent	75.8	18.7	78.1	20.5
Histrionic	25.9	20.2	24.5	19.1
Narcissistic	43.5	21.1	40.4	22.8
Antisocial	36.8	20.9	44.0	20.7
Aggressive	52.5	19.2	57.3	13.4
Compulsive	49.1	18.5	39.4	13.6
Passive-aggressive	67.6	19.9	75.6	16.9
Self-defeating	70.3	19.9	69.0	19.7
Severe personality patterns				
Schizotypal	65.7	22.2	71.7	14.2
Borderline	60.7	19.1	61.2	16.5
Paranoid	75.5	20.7	75.1	14.1
SIDES-SR total	52.2	20.5	49.0	23.6

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3.2 Article 2: Dissociation in Treatment Seeking Refugees in the West

Sabina Palic, MSc Psychology[1]

Jessica Carlsson, Ph.D., MD[2]

Cherie Armour, Ph.D[1&3]

[1] Danish National Centre for Psychotraumatology, University of Southern Denmark, Odense, Denmark

[2]Competence Center for Transcultural Psychiatry Denmark, Psychiatric Center Ballerup, The Mental Health Services of the Capital Region of Denmark, Copenhagen, Denmark

[3] School of Psychology, University of Ulster at Coleraine Campus, Coleraine, Northern Ireland, UK

Abstract

Background: Dissociative experiences are common in traumatized individuals, and can sometimes be mistaken for psychosis. It is difficult to identify pathological dissociation in the treatment of traumatized refugees, because there is a lack of systematic clinical descriptions of dissociative phenomena in refugees. Furthermore, we are currently unaware of how dissociation measures perform in this clinical group. *Aims:* To explore the expression and measurement of dissociative symptoms in Bosnian treatment seeking refugees in Denmark. *Method:* Dissociation was assessed in 86 Bosnian refugees from rehabilitation clinics with a semi-structured clinical interview (Structured Interview for Disorders of Extreme Stress- dissociation subscale) and with a self-report scale (Dissociative Experiences Scale). The performance of the measures was evaluated with ROC analysis. Furthermore, expression of the dissociative symptoms on the two measures is described and discussed. *Results*: The two measures correlated significantly with each other but they showed only moderate classification agreement in ROC analysis. According to the most conservative estimate, 30% of the refugees had pathological dissociation 15 years after their resettlement. Depersonalization and derealization experiences were the most common. Also, a phenomenon of presumably "dissociated" pre- and post-war personality was observed during the interviews. *Conclusions:* Knowledge of dissociative symptoms in traumatized refugees is important in clinical settings to prevent misclassification and to better target psychotherapeutic interventions. Further improvement in the measurement of dissociation in refugees is needed.

Keywords: dissociation, refugees, SIDES, DES, assessment

Background

Dissociation is defined as dysfunction in the normal integration of systems of psychological functioning, encompassing memory, identity, consciousness, perception, and motor control [1]. Elevated rates of dissociative experiences are found in psychiatric patients. For example, depersonalization (*experiencing the self as unreal*) and derealization (*experiencing the surroundings as unreal*) are not uncommon as side effects to medication, during panic attacks, or as a result of substance abuse, psychosis, and sleep deprivation [2]. However, more severe and prolonged dissociative experiences are, in particular, associated with trauma related disorders, like Posttraumatic Stress Disorder (PTSD) [3] and Dissociative Disorders (DD) [1]. Especially, traumatic experiences which involve compromising of the victim's bodily integrity by a perpetrator (e.g., sexual and physical abuse or torture) are considered to be risk factors for the development of pathological dissociation [4, 5]. A continuum of dissociation has been proposed, with PTSD at the lower end and DD at the more extreme end. Each point of the continuum implies decoupling of more functional systems, and further disorganization of individual coherence and function [6] - culminating in the presumed alteration of identities in the Dissociative Identity Disorder (DID) [1]. Dissociative symptoms are furthermore divided into *positive symptoms*, implying intrusion of experiences and sensations into consciousness (e.g., flash-backs, hallucinations, and glimpses of memories and sensations one cannot remember having experienced), and *negative symptoms,* implying deficits or abnormal loss of information in systems of functioning (e.g., amnesia, periodic paralysis, and periodic loss of acquired skills) [7]. If prolonged and chronic, both positive and negative dissociative symptoms cause severe disturbance in an individual's ability to relate appropriately to his/her inner and outer world. Not surprisingly, there is a certain phenomenological overlap between dissociative and psychotic

symptoms. Severe cases of DD can sometimes be difficult to differentiate from psychosis (ibid.).

Dissociation has only been studied extensively in Europe and the USA, but current studies indicate that DD from the DSM-IV and the ICD-10 have validity in countries like Turkey and Puerto Rico [8]. Although culture is known to shape the expression of dissociative phenomena according to regional spiritual and religious beliefs, the extent of such regional idioms is not well designated nor described [8]. Refugees represent some of the most severely traumatized clinical populations, with exposure to trauma over long periods, combined with an accumulation of high risk traumas such as torture, rape, and political imprisonment [9]. It is therefore assumed that there is a high probability of dissociative pathology in refugees who are being treated for trauma-related disorders in the West. Using the Dissociative Experiences Scale Carlson and Rosser-Hogan [10] have reported high levels of dissociative experiences in resettled Cambodian refugees in the USA, while Favaro et al.[11] have described moderate levels of dissociative experiences in refugees from former Yugoslavia. Through the use of diagnostic interviews DD have also been found to be common among tortured Bhutanese refugees [5].

Notably, there is a general lack of studies on dissociation in different refugee populations. Most strikingly, there are no studies of dissociation in clinical samples of refugees resettled in the West. There is also no systematic knowledge of the performance and utility of dissociation measures in this group. Hence, accurate identification of pathological dissociation in western clinical practice with traumatized refugees is very difficult. Recent case reports from a highly specialized clinic in Denmark indicate that around 20-30% of refugee patients show psychosis-like, trauma-related symptoms [12]. Thus, there is a need for studies on the expression and assessment of dissociative phenomena in clinical samples of refugees. More knowledge on

dissociative symptoms in traumatized refugees would ensure that pathological dissociation could be systematically taken into consideration in treatment planning.

Aim

This study aims to evaluate the clinical utility of two dissociation measures, as well as to describe the prevalence and clinical expression of dissociative symptoms in Bosnian treatment seeking refugees in Denmark.

Materials and Methods

Participants

Participants were recruited from six Danish clinics for traumatized refugees. Inclusion criteria were literacy in the Bosnian language and absence of acute suicide risk. Participation ran from May 2010 to May 2011. Danish clinics for refugees treat diverse traumatic symptoms related to war and refugee experiences. Individuals with severe substance abuse and a primary psychotic disorder are referred to other treatments (thus were not included in the current study).The participation varied between clinics (approximately 13-39%). Demographic information is presented in Table 1. Eighty-six individuals completed the assessments. At the time of the assessment 56% had already finished treatment. The Bosnian refugees come from a socialist, multicultural, secularized society, with good living and educational standards, comparable to many of its European neighbors. Detention camps, mass killing, forced deportations, and systematic targeting of women and girls for rape were commonly used methods against Bosnian civilians, resulting in genocide and ethnic cleansing during the 1992-1995 war [13].

Procedure

All participants signed informed consent. The study was conducted in accordance with the Ethical Guidelines for Nordic Psychologists [14] and the ethical guidelines of the clinics. The study is a part of a larger research project. Those 58% from the original study who both filled out a questionnaire and participated in a clinical interview are included in the present study. The questionnaire was sent out seven days before the clinical interview, and returned during the interview. All interviews were conducted in Bosnian by the first author and trained psychology or medical students. The interviewers had basic clinical training in making psychiatric diagnoses.

Measures

The dissociation subscale from the *Structured Interview for Disorders of Extreme Stress* (SIDES) [15] was used to acquire a clinical impression of the dissociative symptoms (referred to as SIDES-D from now on). The SIDES-D is a semi-structured interview, measuring dissociation in relation to Disorders of Extreme Stress Not Otherwise Specified (DESNOS) [15]. Five symptoms are rated on a scale from 0-3, where 2 indicates clinically significant symptoms. Presence of one clinically significant symptom during the last month qualifies for dissociation in DESNOS [15]. The internal consistency of the SIDES-D was .78 in the present sample.

The *Dissociative Experience Scale* (DES) [16] is a well validated self-report screening measure for dissociation [17] with norm material from many different clinical and non clinical populations. Its accuracy has been established according to diagnostic interviews for DD [18]. The DES is scored on a scale from 0-100, indicating the percentage of time that a dissociative experience is present. A mean score of 30 or higher is considered suggestive of pathological dissociation as seen in DD [18]. The internal consistency of the DES in the present sample was .96,

(α = .85 -.89for subscales). All the measures were translated and back translated. Inconsistencies between the translators were determined by consensus.

Statistical Analyses

The data were analyzed with the Statistical Package for Social Sciences (SPSS) 19.0. The highest percentage of missing data at the variable level was 14%. Little's MCAR test indicated that data were missing completely at random. Missing data were imputed with the EM algorithm [19]. Because of skewed data, correlations are reported as Spearman's rho. Receiver Operating Curves (ROC) analysis was used to evaluate classification agreement between the measures [20]. The SIDES-D was used as the reference measure given that it is a clinical interview. The DES was used as a test (the test's accuracy being evaluated against the reference). Sensitivity, specificity, the rate of false positives and false negatives were calculated (sensitivity and specificity were valued equally). The level of agreement between two measures is given by the Area Under the ROC (AUC) [20]. AUC values range from 50 -100%, where 50% indicates a test with no better discriminant validity than what is obtained by chance alone. AUCs of 90% and above indicate good accuracy [20].

Results

No significant differences on the dissociation measures were found between those who had finished treatment and those who had not: *SIDES-D* finished (*M = 4.6, SD = 3.0),* not finished (*M = 3.6, SD = 2.9*); *DES* finished (*M = 24.1, SD = 18.1),* not finished (*M = 24.5, SD = 17.7*). Data from all the subjects were subsequently analyzed as belonging to the same group.

Table 2 describes the prevalence of dissociation, dissociative types, and symptoms. The DES had the most conservative estimate of pathological dissociation, with 30% of the

participants above the cut-off. The SIDES-D indicated twice as high prevalence. SIDES-D and the DES were positively and significantly correlated with each other (*rho*= .62, p < .001). The classification agreement into pathological/non-pathological dissociation was however only moderate. With SIDES-D as the reference, the AUC was 74% (p < .001). The cut off on the DES with the best trade-off between sensitivity and specificity was 19.6 (sensitivity = 73 %, specificity = 86 %, false positive rate = 14%, false negative rate 27%).

Clinical impression of the dissociative symptoms

In the SIDES-D the most pervasive dissociative symptom was derealization (i.e., "*spacing out*" item 3, Table 2). It was characterized by lowered awareness of surroundings while losing track of time for longer periods (often also accompanied by losing track of thoughts and feelings). Also scored on item 3 - when having to go outside, isolated persons reported the surroundings as feeling unreal, sometimes with distortion of sound (e.g. sounds as if coming from far away), and sometimes with distortions of vision (e.g. "melting" faces, faces without eyes, or faces looking unnaturally big). Most derealization experiences lasted momentarily or for a few minutes. However, sometimes the derealization was waxing and waning during whole trips to, for example, the doctor. A few reported tactile distortions during derealization. An example was a man who reported that when walking his rounds at the nearby pond (a trip he made to spare his family when very upset), he had little sense of anything but his emotional turmoil. At the same time he felt as if he was "floating" through the landscape, and did not have any perception of his feet, the movement of feet or the feet touching the ground. The derealization experiences were sometimes accompanied by depersonalization (item 4, Table 2), but depersonalization was in general less common and of shorter duration. Problems with amnesia (item 1, Table 2) were overall not judged to be profound but smaller "slips" of consciousness.

Although most participants *did* have considerable cognitive problems and disorientation in time, it was very difficult to differentiate "amnesia" in the present group from cognitive deterioration due to general psychiatric illness of long duration (i.e. depression, PTSD, and apathy). This problem was especially salient in relation to "*losing track of time in daily activities"* (item 2, Table 2).The SIDES-D question: *"Do you sometimes feel like there are two or more totally different people living inside yourself who control how you behave at different times?"* – was answered positively by many participants and elicited descriptions of "split" pre- and post-war identity. Contrary to the definition of identity alteration [1, 15], the participants did not have the experience of two personalities alternating (in most cases there were also no objective signs of doing things that one could not remember, or profound amnesia). Instead, there was a characteristic experience of a lack of continuity of personal identity.

Self-reported dissociation on the DES

Table 3 shows the means and prevalence of dissociative experiences on the DES. In comparisons with norm material [21] especially high means were found for item no. 3 "*finding yourself in a place, you don't remember going*", no. 13 "*body does not belong to me*", and no. 22 "*act different in different situations so that you almost feel as if you were two different people*".

Discussion

Performance of the measures

The strong positive correlation between the SIDES-D and the DES indicated that they were measuring related concepts. The moderate classification agreement is therefore probably due to the described differentiation problems between symptoms of general psychiatric illness and core dissociative pathology on some SIDES-D items. The same problem has been reported in other studies using SIDES-D [22]. The SIDES-D's tendency towards misclassification is

supported by the finding that the symptom level on the SIDES-D, required for pathological dissociation, best corresponds to a lower than usual cut-off on the DES. The SIDES-D does not specify the *frequency* and *duration* of dissociative experiences in the same way that the diagnostic interviews for DD do (e.g., the Structured Diagnostic Interview for DSM-IV Dissociative Disorders) [23]. Mild dissociative symptoms (as seen in other psychiatric disorders) can therefore be misclassified as being core dissociative pathology. Although it is not a diagnostic interview, SIDES-D was chosen for the exploration of dissociation in refugees because of its brevity. A diagnostic interview for DD has better accuracy, but would require 2-3 hours to complete [23] (4-6 hours with interpretation) and is therefore unfeasible for everyday use in refugee clinics. There are no validated measures of dissociation in refugees. At the same time the present results indicate problems with precise categorization of pathological dissociation with the SIDES-D and the DES. Thus, development of dissociation measures with better psychometrical properties in traumatized refugees is needed. In the meantime, shorter measures such as the SIDES-D which are less precise, but are systematic and enable comparison of dissociation levels with other traumatized populations seem acceptable for getting a clinical impression of dissociation in refugees.

With regards to the level of self-reported dissociative experiences, the DES' precision in detecting DD is good in many different psychiatric populations, but it is lowered in populations with PTSD. This is probably because the PTSD diagnosis contains dissociative trauma-related symptoms as do DD diagnoses. The published norms thus demonstrate that some PTSD populations have means above 30 on the DES even though they do not have DD [16]. Considerable variability in DES scores is reported for different PTSD samples (e.g. between23.6 and 41.1) [24]. More recent studies have reported means of 17.5 [25] and as low as 14.2 [24] for

populations with PTSD and little comorbidity. The large discrepancies in DES scores for individuals with PTSD could be explained by presence of different ratios of the "dissociative PTSD". Indeed, accumulating evidence points to a severe, highly dissociative type of PTSD, with important implications for prognosis and function [26]. The DES cut-off of 30 might therefore have clinical implications in terms of identifying the group with PTSD and especially high dissociation. This corresponds to 30% with possible dissociative PTSD in the current refugee group. However, the utility of the DES in identifying DD in refugees has to be examined against a diagnostic measure of DD.

Symptom expression and differentiation

Dissociation was related to considerable impairment in the current refugees. It was associated with confusion, memory problems, and disorientation, as well as social isolation due to avoidance of situations that trigger dissociation. Lowered awareness with losing track of time occurred as a state of refuge or "numbness" in prolonged periods of emotional suffering. In other instances, derealization and depersonalization occurred in relation to being unable to cope with people or societal expectations (e.g. meetings with the doctor, social services or children's school). Dissociative experiences were primarily triggered by profound feelings of helplessness and uncontrollability. Importantly, although derealization and depersonalization often occurred in fear provoking situations, they were not scored positive if they occurred during panic attacks. Regarding differentiation from psychosis, only hallucinations of direct trauma related content are considered as symptoms of PTSD [1] . When refugees report hallucinations like "melting faces" and hearing of voices (31% of the present group reported hearing voices at least 30% of the time on the DES) differential diagnosis is complicated. However, in accordance with previous studies of traumatized individuals [7, 27] we considered non trauma-related hallucinations without bizarre

or delusional explanations and with intact reality testing as primarily dissociative. Dissociative persons are often said to mostly experience their hallucinations as inexplicable and frightening [7]. Furthermore, they are often subjectively experienced as somehow produced by the self (as opposed to an external source in psychosis) [27]. These differentiating characteristics were found meaningful in the present refugee group as well.

Clinical expression of "split" pre- and post-war identity

In addition to the described dissociative experiences, many participants reported having "two different personalities". This was a secondary finding, and its prevalence was not registered systematically (it was not scored as positive on item 5, Table1). This phenomenon is not considered as DID, but it probably has dissociative elements. The becoming of a "new", different post-war person, stripped of the former positive self-defining characteristics, was described by many. Former self-identifying characteristics felt "detached" and *totally* inaccessible in "current life" (e.g., former CEO of a large company becoming avoidant and unable to speak up for himself in interpersonal conflicts). Related to the stripping of former characteristics were identification problems with the "degraded", "current", "post-war" self - sometimes resulting in a feeling of being "strange" and "unfamiliar" to oneself (depersonalization). Most felt like an "erased person", with no personal characteristics. Many reported feeling so "detached" from the "pre-war" personality, that although they on a cognitive level knew that their experiences before the war happened to them, they felt like someone else's experiences, or as if watching a movie of oneself in different pre-war situations. The worst afflicted also had a decoupling of emotional valence when remembering (especially) positive pre-war experiences (they "knew" that they had felt happy/successful/free in a certain situation, but the memories did not evoke the associated feeling in present time). These "symptoms" of

pre- post-war identity "dissociation" were of different severity. However, when many of the symptoms were present, with elevated scores on dissociation measures, we suspect that they could correspond to moderate DD. For the worst afflicted cases the decoupling of emotional valence was the most striking characteristic. They described a robot-like existence, with no desires or urges -just mechanical going through the notions of life. The state waxed and waned, and exacerbated with the exacerbation of other symptoms of mental illness.

In our view, the "dissociation" of pre- and post-war personality affects general function, because lack of identification with the "post-war" self promotes feelings of self-loathing, apathy, and lack of fundamental self-care. This in turn damages the ability to engage in and profit from treatment, because it is often associated with profound indifference towards the self. The means on items 3, 13, and 22 on the DES for the present group were 6 times higher than what is reported for individuals with PTSD [21], and were at the level for what is observed for DD. All three items pertain to identity alteration, and therefore fit well with the present clinical description of "dissociated" pre- post-war identity. However, as there are no other clinical Bosnian populations to compare the DES norms with, this phenomenon needs further exploration in future studies. Observations of the loss of pre-trauma identity in refugees and victims of torture are not uncommon [28]. They are exemplified in the ICD-10 diagnosis of "Enduring Personality Change After Catastrophic Experience" [29]. There are however no direct references to dissociation in this diagnosis. More studies are needed to explore consequences of the presumably dissociated pre- and post-war personality for the over-all function of the treatment seeking refugees. In particular, the severity of this phenomenon should be researched in relation to other dissociative symptoms and established DD diagnoses.

With regards to treatment, Cloitre and colleagues [30] have shown that dissociation can be targeted before the processing of traumatic experiences. For women with childhood abuse, PTSD, and high dissociation, a module of Skills Training in Affective and Interpersonal Regulation (STAIR) followed by a module in Narrative Story Telling (NST) had superior effects to either module alone. Those with high dissociation receiving both modules had further treatment gains during the 6-month follow up, while those with high dissociation and no stabilizing phase (STAIR) showed deterioration in the same period. For those with PTSD and low dissociation, all treatments were equally effective. The possible benefits of STAIR and NST adapted to traumatized refugees with high dissociation should be explored.

Limitations

This study represents a selected clinical population of former Bosnian refugees. Because of the high burden of assessment in the larger study, and the low level of participation, we suspect that only the best functioning individuals volunteered to participate. Pathological dissociation could therefore be more prevalent in more representative samples of treatment seeking refugees in the West. The expression of dissociative symptoms might be different in other refugee cultures. Inter-rater agreement was not examined.

Conclusions and recommendations

High dissociation was prevalent in the present clinical group of refugees 15 years after resettlement, and despite the fact that 56% had undergone treatment. Development of measures which can indicate core dissociative pathology in refugees with more precision are needed. The development of short screening measures would be desirable in the refugee treatment setting. To better understand the etiology and expression of dissociation, known correlates to core dissociative pathology (e.g. childhood maltreatment) should also be

systematically studied in traumatized refugees. Screening for dissociation should ideally precede treatment in order to establish the general level of functioning and to plan the treatment. If not assessed in due time, dissociative symptoms might surface late in the treatment and create confusion in the clinician's perception of the patient or be misclassified as psychotic symptoms.

3.2.1 **Table 1**

Demographic information (N = 86)

	%	Mean	SD	Range
Female	51	-	-	-
Age	-	46	8.2	30-67
Years since resettlement	-	15	3.4	3-20
Years of education:		11.6	2.4	5-16
> 8	1	-	-	-
8 (primary school)	21	-	-	-
≤12	78	-	-	-
War trauma exposure:	-	12.8	3.8	0-21
Torture	66	-	-	-
Beating	55	-	-	-
Detention camp imprisonment	49	-	-	-
Rape and other sexual assault	34	-	-	-

3.2.2 **Table 2**

Prevalence of Dissociation, Dissociation Types, and Symptoms Across the Measures (N= 86).

	Above cut off %	Mean	SD
SIDES-D			
Symptom (≥2):			
1. Amnesia	21	0.7	0.9
2. Losing track of time	38	1.2	0.9
3.”Spacing out”	38	1.1	1.0
4. Feeling unreal	22	0.7	1.0
5. Identity Alteration	9	0.4	0.6
Total	65	4.1	3.1
DES			
Sub-scale (≥ 30):			
Amnesia	23	18.6	16.4
Absorption	44	30.7	20.7
Depersonalization	24	18.0	17.7
Total	30	24.0	17.8

DES =Dissociative Experiences Scale, *SIDES-D* = Structured Interview for Disorders of Extreme Stress- Dissociation Subscale

3.2.3 **Table 3**

Means and Prevalence of Dissociative Experience Scale (DES) Items ≥ 30, and Their Distribution Across the DES-positive and DES-negative Groups.

Item no.	DES	M (SD)	Item positive total (N = 86)	Item positive if DES positive (n =26)	Item positive if DES negative (n = 60)
	Absorption subscale				
1	Don't remember what happened while driving	36.2(28.9)	57%	89%	44%
2	Not hearing part/all of what is said	45.3(29.7)	67%	100%	53%
14	Remembering vividly as if reliving	43.5(32.5)	64%	89%	52%
15	Not sure whether things happened or were just a dream	28.4(29.5)	44%	77%	28%
16	Finding familiar place unfamiliar	21.2(24.6)	35%	89%	10%
17	Easily absorbed in TV- show	32.6(30.9)	56%	77%	47%
18	Deeply involved in fantasy	21.5(28.9)	28%	73%	8%
20	Staring off into space….	36.4(29.8)	59%	89%	45%
22	Act different in different situations	24.3(24.5)	41%	80%	23%
23	Does usually difficult things with ease	24.4(27.7)	39%	77%	25%
	Amnesia subscale				
3	Finding self in a place, you don't remember going	22.4(26.4)	38%	81%	20%
4	Finding self dressed in clothes you don't remember putting on	16.2(23.3)	27%	63%	10%
5	Finding new things you do not remember buying	21.2(25.6)	33%	83%	10%
6	Called by different names	15.6(22.4)	20%	54%	5%
8	Don't recognize friends and family	14.0(21.3)	22%	50%	7%
9	No memory for important life events	21.9(28.5)	31%	73%	14%
10	Accused of lying when haven't lied	16.3(22.3)	23%	50%	12%
25	Evidence of doing things you don't remember	24.1(23.9)	35%	77%	17%
26	Finding writings and drawings you do not remember doing	20.1(23.7)	31%	58%	20%
	Depersonalization subscale				
7	Standing next to yourself…	12.3(18.9)	19%	53%	3%
11	Don't recognize self in a mirror	16.8(22.4)	33%	58%	20%
12	Surroundings look unreal..	16.1(21.6)	30%	65%	14%

13	Body does not belong to me	24.6(26.2)	44%	80%	30%
27	Hear voices inside the head	20.6(26.1)	31%	70%	15%
28	Looking at the world through a fog..	17.8(22.6)	28%	74%	7%
	(does not belong to a subscale)				
19	Able to ignore pain	19.6(25.8)	28%	65%	12%
21	Talk aloud to one self when alone	29.5(31.1)	45%	92%	24%
24	Can't remember if you have done something or just thought of it	37.2(29.9)	58%	96%	42%

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4 Chapter 4: Articles from the HoNOS study

4.1 Article 3: Norms for Refugee Outpatients and Psychiatric Inpatients on the Health of Nation Outcome Scales (HoNOS) – The HoNOS as a Common Measure

Sabina Palic, MSc Psychology, Danish National Centre for Psychotraumatology, University of Southern Denmark, Denmark

Michelle Lind Kappel, MSc Psychology, Clinic for PTSD and Transcultural Psychiatry (CPTP), Aarhus University Hospital, Denmark

Monica Stougaard Nielsen, MSc Psychology, Ph.D., Clinic for PTSD and Transcultural Psychiatry (CPTP), Aarhus University Hospital, Denmark

Jessica Carlsson, MD., Ph.D., Competence Center for Transcultural Psychiatry Denmark, Psychiatric Center Ballerup, The Mental Health Services of the Capital Region of Denmark,

Copenhagen, Denmark

Per Bech, MD, DSci , Psychiatric Research Unit, Psychiatric Center North Zealand, Hillerød, Denmark

Abstract

Purpose: To provide clinical norms for the evaluation of social and psychiatric impairment among traumatized, treatment-seeking refugees in the West. Clinical norms are necessary for informing interdisciplinary decisions made by professionals regarding this population.

Methods: Psychiatric and social impairment was assessed routinely at pre- and post-treatment using the Health of Nation Outcome Scales (HoNOS) at three specialized Danish refugee clinics over a 3-year period, and at a Danish psychiatric hospital over a 10-year period. The HoNOS profiles and HoNOS improvement rates of 448 refugee outpatients were compared to those of inpatients with a primary diagnosis of schizophrenia (N = 3175), addiction (N = 950), dementia (N = 656), affective disorders (N = 3081), anxiety disorders (N = 1781), and personality disorders (N = 1030).

Results: Despite their outpatient status, traumatized refugees revealed higher levels of psychiatric and social impairment at pre-treatment compared to most inpatients. Moreover, the refugee outpatients obtained a specific profile on the HoNOS, one that is best characterized by high problems overall. The expected rate of pre- to post-treatment improvement on the HoNOS was smaller for the refugee outpatients than it was for the psychiatric inpatients.

Conclusions: The HoNOS profile of the refugee outpatients points to complex problems. Thus, the broad assessment of symptoms as well as better cooperation from psychiatric, health care, and social systems is necessary in order to meet the treatment needs of this group. The use of common psychiatric measures such as the HoNOS is an important part of the process.

Keywords: functional impairment, HoNOS, refugee, treatment

Introduction

Treatment-seeking refugees resettled in the West experience many stressors before their arrival at a host country [1]. They are often exposed to multiple traumas before and during migration, and many also experience post-settlement difficulties such as language barriers, culture shock, and loss of social status and social networks [2]. These stressors place refugees at high risk of developing different psychiatric disorders. In current research, the mental health issues experienced by refugees in the West are often interpreted in the light of a few psychiatric disorders, the most common being posttraumatic stress disorder (PTSD), depression, and anxiety [3]. In clinical settings, a range of other problems are typically encountered, however, they are often difficult to document as there are only a few validated measures available for the assessment of symptoms in this group [4]. There are currently no applied or validated global measures of psychiatric impairment for traumatized refugees [4]. Consequently, the current understanding of the complex conditions experienced by traumatized refugees resettled in the West is limited. Moreover, as refugees often seek treatment for trauma-related problems many years after having resettled in the West, most are rightly considered to be former refugees (with permanent residence of citizenship) by the time they encounter Western psychiatric systems. As such, traumatized refugees constitute a subgroup of psychiatric patients in Western countries whose needs are generally poorly understood and poorly documented.

To the best of our knowledge, there are currently no studies that describe the level of global psychiatric impairment in representative groups of traumatized refugees from Western clinics. Neither are there any studies that have compared the level of global impairment among former refugees with that of other patients from the same mental health services in the West. The dissemination of representative norms regarding levels of global impairment among traumatized

refugee patients is likely to improve cooperation between specialized refugee clinics and other parts of the social and psychiatric systems, especially when it comes to the facilitation of a much needed mutual understanding of the overall severity of symptoms and social impairment in this population.

The Health of the Nation Outcome Scale (HoNOS) was developed for the routine monitoring of psychiatric patients in the National Health Service of the United Kingdom [5]. It is an observer-rated scale that covers psychological symptoms as well as behavioral, organic and social problems. The HoNOS has been employed and validated across a variety of psychiatric populations in England as well as other Western countries. A Danish translation has also been validated [6], and it is currently being employed across a wide range of psychiatric populations in Denmark. The HoNOS has good concurrent, content, and predictive validity, as well as adequate inter-rater reliability and sensitivity to change [7]. It is considered to have psychometric properties corresponding to, or even better than, other psychiatric, observer-rated routine measures [7], of which the Global Assessment of Functioning (GAF) [8] is probably the best known. One small study concerning 50 HoNOS case files on refugees and asylum seekers within London community psychiatry found that these service users had elevated levels of impairment [9]. Nevertheless, these findings require substantiation from larger studies of more representative groups of patients from other Western countries.

In the present study, norms on the HoNOS are provided for consecutive groups of traumatized refugee patients and compared to large consecutive groups of patients from other parts of the Danish psychiatric services. Specific problems experienced by traumatized refugees are highlighted. Rates of improvement on the HoNOS for each group are compared in order to aid understanding about prognosis. Thereafter, the utility of the HoNOS regarding the treatment

of the traumatized refugees is discussed.

Method

HoNOS ratings for refugee outpatients from three departments (Aarhus, Horsens, Randers) at the Clinic for PTSD and Transcultural Psychiatry (CPTP), Aarhus University Hospital, were collected at intake and discharge over a 3-year period. CPTP is a specialized center for the treatment of trauma and torture within the psychiatric services of the Danish mental health system. HoNOS ratings were collected as part of the standard assessment of refugees at CPTP. The comparison group consisted of psychiatric inpatients at the Psychiatric Center North Zealand (PCNZ), which is a general psychiatric hospital within the Danish mental health system. HoNOS ratings for psychiatric inpatients were collected at intake and discharge over a 10-year period as part of the standard service evaluation at PCNZ [10, 11].

Refugee treatment setting and procedures

All refugee outpatients who started and finished treatment at one of the three CPTP departments during the period of May, 2009 to April, 2012 were eligible as participants. Individuals are referred to CPTP when exposure to refugee experiences and war trauma are suspected to be the main cause of their psychiatric problems. Moreover, individuals must have a diagnosis of one or more of the following ICD-10 [12] disorders in order to qualify for treatment: *depressive disorders* (F32-34), *anxiety disorders* (F40-49), and, *Enduring Personality Change after Catastrophic Experience* (F62.0). Individuals who fulfill the criteria for a primary *psychotic disorder* and/or severe *substance abuse* are not eligible for treatment at CPTP and are referred to other treatments. Treatment at CPTP is conducted in an outpatient setting and includes psychotherapy and physiotherapy once weekly, as well as counseling in relation to psychoactive

medication and social issues. The average length of treatment for the refugee outpatients in the present study was approximately 4 months (*M* = 130.5 days, *SD* = 56.61, *Range*: 7- 345 days). Demographic information and HoNOS ratings (at pre- and post-treatment) were obtained by the psychologists. The refugee outpatients were rated on the HoNOS by the same psychologist with whom they attended psychotherapy. Eleven different psychologists were working at CPTP at the time of the present study. The first HoNOS administration had to be completed by the fourth treatment session at the latest (including one session of pre-treatment assessment).

Psychiatric inpatient setting and procedures

Individuals who were inpatients at PCNZ for more than 24 hours during the years 2000 to 2009 were included in the comparison group [10, 11]. The psychiatric inpatients were diagnosed according to the ICD-10 [12]. All major diagnoses were represented in the comparison group (see Table 2). The inpatient group received standard psychiatric treatment according to their condition. Length of admission also varied according to condition. Further details can be found in [6]. The HoNOS was administered by psychiatric nurses no longer than 24 hours after intake and again at time of discharge. Patients who were admitted to the hospital several times during the course of one year feature only once in the present dataset. The study was approved by Århus University Hospital and PCNZ according to ethical rules for data collected as a part of routine practice. Informed consent is not requested from the patients when routinely collected data are analyzed retrospectively for research purposes.

Characteristics of the Danish mental health system

Inpatient care is offered to individuals who display the most severe psychiatric impairments and who typically are in need of acute stabilization due to concerns about their own

safety or the safety of others. The main purpose of psychiatric inpatient care is to identify the most pertinent psychiatric problems and to initiate appropriate treatment. The duration of hospitalization is kept to a minimum. After appropriate stabilization, patients may be discharged and referred to outpatient treatment within community psychiatry. The primary goals of outpatient treatment are to treat social impairments related to psychiatric illnesses and to work on the regulation, compliance, or supported withdrawal of medication. Specialized outpatient treatments exist for individuals who have relatively discrete psychiatric disorders and who are assumed to be able to benefit from evidence-based therapies. CPTP represents one of these specialized clinics. The primary expertise of CPTP is transcultural psychiatric issues. Social psychiatric initiatives exist for the most socially impaired psychiatric patients. The aim of these initiatives is to improve individuals' general quality of life and to secure possibilities for inclusion and societal participation e.g. by providing at-home personnel for support with everyday activities/tasks and access to sheltered work or leisure activities.

Measures

Health of Nation Outcome Scale [5]: Each item on the HoNOS is scored on a scale of 0-4 by a clinical observer. Higher scores indicate greater levels of impairment. Scores on the HoNOS items are summed up to produce a total score, reflecting overall levels of impairment. Scores of 2 or higher within specific areas indicate levels of impairment that require clinical attention. Studies have shown that HoNOS scores ≥ 12 are typically seen in inpatients [13]. The initial HoNOS rating is usually carried out as soon as possible after the patient has made contact for the first time, although the timing of HoNOS evaluations can vary according to the specific treatment context [5]. Ratings of comorbidity (item 8) for the inpatients in the present study were

limited to anxiety. Ratings of comorbidity for the refugee outpatients were not limited to any particular disorder. The comorbidity deemed by clinicians to be the most severe was rated on item 8 (if not already rated on items 6 or 7).

Data analyses

Statistical analyses were performed using SPSS for Windows 20.0 (SPSS Inc.).The highest percentage of missing data (at the variable level) was 16% for the refugee outpatients. Little's MCAR test indicated that data were missing completely at random. Missing HoNOS data were imputed using the Expectation Maximation Algorithm [14] in SPSS. Data for inpatients were not imputed. Data are described as frequencies and percentages. Differences in pre-treatment HoNOS scores between the refugee outpatient- and psychiatric inpatient groups were assessed using independent sample t-tests. Due to the large sample sizes, only t-tests obtaining $p < .01$ after Bonferonni adjustments for 78 repeated tests were considered to be statistically significant. Due to the risk of small differences becoming significant in large sample sizes, the magnitude of the differences in pre-treatment HoNOS scores between the refugee outpatient- and psychiatric inpatient groups are also reported as Cohen's d/standardized effect sizes (ES), which have been corrected for unequal group sizes [15]. Generally speaking, $ES = 0.2$ indicates a small effect size (i.e. 85% overlap of scores between the two groups), $ES = 0.5$ indicates a medium effect size (i.e. 67% overlap of scores between the two groups), and $ES = 0.8$ indicates a large effect size (i.e.53% overlap of scores between the two groups).

Results

Approximately 93 % of the refugee outpatients and 90 % of the psychiatric inpatients were assessed with the HoNOS. The refugee outpatients ($M = 40.5$ years, $SD = 8.56$, *range*: 20-61 years) were younger than the psychiatric inpatients ($M = 46.8$ years, $SD = 20.6$). 45

% of refugee outpatients and 55 % of psychiatric inpatients were women. The average (mean) length of resettlement in Denmark for the refugee outpatients was 12.5 years (*SD* = 6.4). Characteristics of the refugee outpatients are presented in Table 1.

Profiles of psychiatric and social impairment at pre-treatment

Table 2 presents descriptive statistics and highlights significant comparisons ($p < .0001$) between the refugee outpatients and all other groups on the HoNOS. Table 3 presents differences in average HoNOS scores acquired by refugee outpatients and psychiatric inpatients, with corresponding 99% Confidence Intervals (CI). Table 4 presents standardized effect sizes (ES) which correspond to the observed differences. Table 2 indicates that the average total HoNOS severity rating for the refugee outpatients was high in comparison to the psychiatric inpatients. 78.3 % of the refugee outpatients had a total HoNOS severity rating of 12 or higher at pre-treatment. The HoNOS profile for the refugee group reveals that they were rated as needing clinical attention (mean scores ≥ 2) on three HoNOS domains; *depressed mood*, *comorbidity*, and *problems with relationships*. The profiles of psychiatric inpatients typically had fewer areas requiring clinical attention. They corresponded to the main problem area(s) of their diagnoses (e.g. drinking/drug taking in patients with addiction).

Behavioral domain: The refugee outpatients scored significantly *higher* than most groups of psychiatric inpatients on *overactive and aggressive behavior* corresponding to medium to large ES's. The refugee outpatients acquired significantly *lower* scores on *non-accidental self-injury* compared to most inpatient groups, but the ES's were small. The refugee outpatients also scored significantly *lower* than most groups of psychiatric inpatients on *drinking/drug taking problems* (*ES* = 0.48 – 2.8).

Organic problems: The refugee outpatients scored significantly *lower* than the inpatients

with dementia on *cognitive problems* (*ES* = .47), but significantly *higher* than other groups of psychiatric inpatients. The latter group differences represented medium to very large ES's. Regarding *physical illness,* the refugee outpatients scored significantly *higher* than all groups of psychiatric inpatients apart from those with dementia; group differences represented large to very large ES's.

Psychological problems: The refugee outpatients scored significantly *lower* than the inpatients with schizophrenia and dementia on *hallucinations and delusions* (large to very large ES's). The refugee outpatients scored significantly *higher* than all groups of psychiatric inpatients on *problems with depressed mood* (large to very large ES's), however, the difference in scores between refugee outpatients and inpatients with affective disorders was of little clinical importance (*ES* = 0.31). Finally, the refugee outpatients displayed significantly *higher* levels of comorbidity/anxiety than all groups of psychiatric inpatients; all group differences represented large or close to large ES's. The most prevalent comorbidities for refugee outpatients were anxiety (31%), hyper-vigilance related to PTSD (25%), and sleep disturbance (16%).

Social problems: The refugee outpatients scored significantly *higher* than all groups of psychiatric inpatients on *problems with relationships*. The group difference represented small to large ES. Significant differences in scores *on problems with activities and daily living* were found between refugee outpatients and all groups of psychiatric inpatients. Refugees scored significantly *higher* than all inpatients (*ES* = .17-.87) apart from those with dementia. With regards to scores *on problems with living conditions*, few statistically significant differences with small ES's were found between refugee outpatients and psychiatric inpatients. Refugee outpatients had significantly higher scores on *occupational problems* than patients with affective-, anxiety-, and personality disorders (medium sized ES's).

Finally, the total level of psychiatric and social impairment for refugee outpatients reflects the general tendency of this group to score highly on the HoNOS. The average (mean) total HoNOS severity rating for the refugee outpatients was found to be significantly *higher* than that for inpatients with schizophrenia ($p < .0001$), addiction ($p < .0001$), affective- ($p < .0001$), anxiety- ($p < .0001$) and personality disorders ($p < .0001$). It was comparable to that of dementia inpatients. In terms of clinical importance, the mean difference in total HoNOS scores between refugee outpatients and inpatients with addiction was small (*ES* = .38). The mean difference in total HoNOS scores between refugee outpatients and inpatients with schizophrenia represented a medium ES. The refugee outpatients acquired considerably higher total HoNOS severity rating compared to inpatients with affective-, anxiety-, and personality disorders (*ES* = 1.0 to 1.31).

The rate of pre- to post-treatment improvement on the HoNOS

As can be seen in Table 5, the rate of pre- to post-treatment improvement on the HoNOS for refugee outpatients was 10%. The rate for psychiatric inpatients ranged between 23 to 49 %. The refugee outpatients showed the largest improvements in relation to *behavioral problems* and some *psychological symptoms*. The psychiatric inpatients demonstrated a greater all-round improvement. All groups showed less improvement in relation to *social problems* compared to other areas of impairment.

Discussion

The present findings indicate *higher* overall levels of psychiatric and social impairment among refugee outpatients compared to most psychiatric inpatients, who by definition are in the most acute phase of their respective disorders. There is no obvious reason to suspect that systematical overrating took place at CPTP or PCNZ. The data were collected on a routine basis by the clinical staff at both treatment venues. Moreover, similar levels of

impairment on the HoNOS have been reported for asylum seekers and refugees within community treatment in London [9]. Thus, the fact that similar HoNOS profiles have been reported for refugee outpatients in different psychiatric contexts makes it less probable that systematic overrating took place at CPTP.

A number of important characteristics associated with the refugees in the present sample may help explain the overall high levels of impairment found within this group. The average length of time between resettlement in Denmark and the time at which treatment was sought by refugee outpatients was very long (M = 12 years). This may have contributed to the chronification of symptoms of psychiatric illnesses among the refugees in this group, and, consequently higher levels of impairment. Moreover, the very high levels of impairment found among refugee outpatients may also be closely linked to the risk factors associated with migration and the experience of being a refugee. Patients who, aside from having a psychiatric illness, also display severe problems when it comes to participating in society, maintaining a healthy economy, and establishing social networks are often considered to be the most chronic and severe psychiatric patients. Refugees are particularly vulnerable because they often experience many challenges associated with migration as well as various post-settlement difficulties. In a 10-year follow-up study of tortured, treatment-seeking refugees , it was found that post-settlement difficulties had a negative effect on psychiatric morbidity, and that this effect increased over time [16]. Thus, given that refugees are generally not exposed to protective factors such as social support, employment, and societal inclusion, it is not surprising that overall high levels of impairment were found among refugee outpatients in this study.

With regards to specific profiles of impairment on the HoNOS, the present findings indicate that the HoNOS scores obtained by the refugee outpatients are clearly discernible only

from those obtained by the inpatients with schizophrenia and dementia. That is, the inpatients with schizophrenia and dementia scored consistently higher on the core problem areas within their diagnostic groups (e.g. inpatients with schizophrenia scored higher on *hallucinations/delusions* and inpatients with dementia scored higher on *cognitive problems* and *physical illness*) compared to the refugee outpatients. Apart from this, refugee outpatients often received higher or equally high ratings on core problem areas of other diagnostic groups. Importantly, the largest difference in total HoNOS severity ratings was observed between refugee outpatients and the group of inpatients with anxiety disorders (*ES* = 1.31). Diagnostically speaking, most refugee outpatients are considered to belong to precisely this group given that they are often diagnosed with PTSD. However, the present results indicate that this is not an appropriate comparison group. The impairment profile of the refugee outpatients is much more versatile and much higher. Due to the highly versatile nature of the HoNOS profile obtained by the refugee outpatients, it is thus not immediately clear as to which large diagnostic groups these individuals should be compared to. This highlights the need for a broader assessment of symptoms among traumatized refugees in general. Careful consideration needs to be taken regarding the choice of primary diagnosis and possible comorbid disorders when dealing with this group.

When considering the versatility of the HoNOS profile obtained by the refugee outpatients in the present study, one might also ask whether it is possible for refugees to present with all the comorbidities and impairments that were exhibited. Although there are, as yet, no appropriate diagnoses that capture the complex and chronic trauma adaptations among refugees, very broad problem profiles have been identified e.g. Disorders of Extreme Stress Not Otherwise Specified (DESNOS) [17] and Enduring Personality Change after Catastrophic Experience

(F62.0) [12]. However, these problem profiles do not work well as diagnostic entities [18]. Moreover, there is no obvious treatment of choice for broad and complex trauma adaptations among refugees, and the prognosis is unknown. Further research is needed in order to identify best treatment practices and the prognosis for traumatized refugees in psychiatric care. Finally, as a consequence of the present research, referral to social psychiatric initiatives should be considered as an option for the portion of traumatized, former refugees that are worst afflicted. In reality, this is not a plausible option given that Western social psychiatric services are often not well enough equipped to meet the needs of patients with cultural backgrounds that differ from the majority population.

Differences in the rates of improvement on the HoNOS

The second aim of the present study was to describe the rates of pre- to post-treatment improvement on the HoNOS for the refugee outpatients and the psychiatric inpatients. This part serves as an illustration of expected rates of improvement in traumatized refugees in an everyday treatment. While pre- to post-treatment change on the HoNOS *was* registered for the refugee outpatients, the rate of improvement was much smaller and more uneven compared to that of psychiatric inpatients. However, previous studies of the same refugee outpatients have found that the magnitude of improvement on the *psychological symptom* domain of the HoNOS was slightly higher but comparable to rates of improvement on the symptom measures of PTSD (Kappel & Stougaard, submitted). Therefore, although the rate of improvement on the HoNOS was small for the refugee outpatients, it is likely that the HoNOS captured some meaningful change in this group.

When attempting to explain disparities in the rates of improvement on the HoNOS between refugee outpatients and psychiatric inpatients, some of the improvement associated with

the psychiatric inpatients has to be attributed to the acute- rather than the chronic state of the inpatients. Greater improvement on the HoNOS can be expected during the stabilization phase of inpatients that are in the acute stage of psychiatric illness. Another important point is that the refugee outpatients probably didn't receive the same rigorous psychopharmacological treatment as did the psychiatric inpatients. This may help explain the more even improvement on the HoNOS among the psychiatric inpatients and the smaller, more uneven improvement among the refugee outpatients. The vast majority of the psychiatric inpatients received well-controlled, psychopharmacological treatment during hospitalization. Given that the refugee outpatients revealed higher or equally high levels of impairment on the HoNOS compared to the psychiatric inpatients, it is likely that they also would have benefited from psychopharmacological treatment. However, compliance is always more difficult to achieve in outpatient treatment settings. And it represents an especially clinically well-known challenge associated with groups of traumatized refugees. The high levels of impairment on the HoNOS found among refugee outpatients in the present study points to the need for better integrated psychopharmacological treatment when it comes to the specialized treatment of traumatized refugees (involving general practitioners is not advised due the already established complexity of the psychiatric problems displayed by refugee outpatients on the HoNOS).

One way of establishing a more suitable treatment for the worst afflicted traumatized refugees could be through the use of a two-phase model. In this model, psychiatrists and psychiatric nurses initiate the medical treatment, and psychotherapy and physiotherapy are postponed until compliance and stabilization is accomplished. This is of course not to imply that psychopharmacological treatment should replace therapeutic and social interventions for traumatized refugees. The HoNOS profiles of the refugee outpatients in the present study clearly

indicate the need for different treatment options that can tackle the diverse symptoms and social problems associated with this group. Most importantly, professionals who do not work with traumatized refugees on a daily basis should be aware of the fact that the rates of expected improvement for this group are likely to be modest, even in situations where the best current treatments have been made available.

Clinical Utility of the HoNOS in refugee populations

The employment of the HoNOS as a measure of psychiatric and social impairment among traumatized, refugee outpatients was overall found to be meaningful at the three CPTP departments. The instrument covers a range of problems that are typically encountered in psychiatric populations. As indicated by the present findings, traumatized, treatment-seeking refugees experience most of these problems as well.

There are a number of special concerns related to the use of the HoNOS among refugee outpatients. Firstly, due to the complexity of assessing social issues among individuals with different cultural backgrounds and the need for interpretation in refugee treatment settings, the information available to clinicians at pre-treatment was experienced to be incomplete in relation to social problems (e.g. *problems with relationships*, *activities-daily living*, and *living conditions*). This was usually dealt with by adding questions about social problems directly to the initial assessment interview. Psychologists were also given three additional sessions in which to rate the HoNOS because the need for interpretation usually cuts the amount of information that can be acquired during a single session by one half. The employment of the HoNOS among refugee outpatients would probably not have been feasible if it weren't for these adjustments. Secondly, with regards to item 8 (comorbidity), it was often difficult to determine which of the

patients' comorbidities was the most central and most severe. However, this may represent a general problem associated with the HoNOS given that similar problems have also been reported in relation to other psychiatric populations [7]. The HoNOS shows its clinical utility in traumatized refugees in by guiding initial decisions about the kind of psychiatric help that should be offered to patients in general. That is, it identifies the primary focus of treatment (e.g. stabilization, social interventions or treatment of symptoms) as well as the type of progress that can be expected for particular individuals according to the overall severity and centrality of their problems. Moreover, the strength of the assessment of global psychiatric outcomes with the HoNOS also lies in the ability to reliably inform other professionals about the status of patients when responsibility is being transferred from specialized refugee clinics to other treatments and social services. Another quality of the HoNOS is that it is an observer-rated instrument. Thus, it does not require translation, which makes it easy to employ as a routine measure in patient populations that are characterized by many different languages.

Cross cultural considerations

The employment of Western psychometric scales in other cultures is generally not advised unless verification of their applicability has been provided. It is worth noting that many of the CPTP patients in the present study were former refugees who had been living in Denmark for over a decade. Although the refugee outpatients may not have been well integrated into the Danish way of life, the same societal responsibilities and expectations as all other citizens and psychiatric patients were placed upon them. In this case, it is necessary to evaluate the global psychiatric and social functioning of treatment seeking refugees in relation to the role expectations of the society in which the individuals live. The consequences of not doing so may prove to be detrimental for the individual because the provision of services cannot be matched to

the need for help in a consistent manner. This raises the risk of traumatized former refugees "falling through" the cracks of the treatment and social systems, and not getting the required help and support to maintain a worthy existence.

Limitations

While published reports regarding inter-rater agreement on the HoNOS can be found at PCNZ [6], inter-rater agreement on the HoNOS was not assessed at CPTP. This contributes to some uncertainty regarding the HoNOS ratings acquired by refugee outpatients. On the other hand, the large number of raters from the three different departments at CPTP reduces the likelihood of systematic bias. A direct comparison cannot be made between the levels of comorbidity in the refugee outpatient and psychiatric inpatient groups, because the first were rated on comorbidity and the latter were on anxiety. However, the levels of comorbidity/anxiety can be understood as reflecting the most pertinent comorbidity problems associated with each group. The present norms were collected at only one hospital and at three departments comprising one specialized refugee clinic. However, given that the hospital and the refugee clinic are part of the Danish national mental health system, of which everyone has equal access to in general, the selection bias associated with the present norms is likely to be small.

Conclusions

The HoNOS has good utility among traumatized, treatment-seeking refugees. A clear improvement of applying the HoNOS to this population is that the specific problem profiles of refugees can be compared to those of large groups of other psychiatric patients whom psychiatric professionals and social workers are more familiar with in general. This aids informed decision making in settings which do not encounter traumatized refugees on a regular basis. Given the small risk of selection bias associated with the present sample of refugee patients, the present HoNOS norms may apply to traumatized refugee outpatients in other European countries as well given similar demographic compositions and treatment-seeking patterns. Professionals in the West, who do not encounter traumatized refugees on a daily basis, should be aware of the severe and complex psychiatric and social impairment- as well as modest rates of improvement associated with this group. There is a need for better cooperation between the psychiatric and social systems, especially when it comes to the traumatized refugees who are worst afflicted. Future studies that aim to further qualify the validity of the HoNOS in the psychiatric population of traumatized refugees should be of longitudinal design, and they should explore whether patients' status on the HoNOS is predictive of long-term adjustment and differential outcomes.

4.1.1 **Table 1**

Demographic information

	Refugee outpatients
	N (% of total)
Country of origin [a] (n = 446)	
The Balkans	116 (25.90)
The Middle East	291 (64.95)
Other	39 (8.7)
Years of formal education	
0	38 (9)
1-5	54 (12.1)
≤ 10	173 (38.6)
Trauma history	
(mutually overlapping groups)	
Imprisonment	160 (35.71)
Torture	140 (31.25)
War	417 (93.10)
Need of interpreter (n = 445)	284 (63.39)

a Balkans (Kosovo, Bosnia & Herzegovina, Serbia, Georgia, Montenegro, Macedonia, Croatia), Middle East (Iraq, Iran, Lebanon, Jordan, Kuwait, Syria, Yemen, Afghanistan), Other (Somalia, Sri Lanka, Indonesia, Congo, Vietnam, Ethiopia, Colombia).

4.1.2 **Table 2**

Means, Standard Deviations, and Significant Comparisons for HoNOS Ratings.

	HoNOS item	Refugee outpatients n = 448 (SD)	Schizophrenia (F20-29) n = 3175 (SD)	Affective Disorders (F30-39) n = 3081 (SD)	All Anxiety Disorders (F40-49) n = 1781 (SD)	Personality Disorders (F60-69) n = 1030 (SD)	Addiction (F10-19) n = 950 (SD)	Dementia (F00-09) n = 656 (SD)
	Behavioral problems							
1	Overactive, aggression	1.14 (0.82)	0.67* (1.04)	0.39* (0.81)	0.36* (0.78)	0.49* (0.89)	0.63* (1.04)	1.09 (1.27)
2	Non-accidental self-injury	0.46 (0.71)	0.34 (0.85)	0.50 (1.06)	0.79* (1.29)	0.74* (1.19)	0.59 (1.13)	0.24* (0.75)
3	Problem-drinking or drug taking	0.12 (0.47)	0.64* (1.14)	0.47* (0.97)	0.55* (1.03)	0.74* (1.18)	**2.73*** (1.11)	0.34* (0.91)
	Organic problems							
4	Cognitive problems	1.60 (0.76)	0.76* (1.01)	0.52* (0.87)	0.29* (0.67)	0.36* (0.71)	0.82* (1.11)	**2.14*** (1.36)
5	Physical illness	1.70	0.52*	0.79* (1.12)	0.62* (1.07)	0.56* (0.97)	0.87* (1.17)	1.54 (1.40)

		(0.98)	(0.99)					
	Psychological problems							
6	Hallucinations/delusions	0.60 (1.0)	**2.10*** (1.30)	0.48 (0.97)	0.32* (0.77)	0.57 (1.0)	0.73 (1.17)	1.38* (1.32)
7	Depressed mood	**2.20** (0.84)	0.88* (0.88)	1.87* (1.11)	1.48* (0.93)	1.42* (0.91)	1.13* (0.96)	0.93* (0.96)
8	Comorbidity/Anxiety	**2.90** (0.92)	**2.09*** (1.10)	1.96* (1.10)	**2.04*** (1.10)	**2.11*** (1.03)	1.87* (1.17)	**2.06*** (1.26)
	Social problems							
9	Problems with relationships	**2.10** (0.93)	1.58* (1.27)	1.04* (1.15)	1.02* (1.17)	1.43* (1.18)	1.27* (1.23)	1.66* (1.43)
10	Problems with activities and…	1.30 (0.83)	1.11* (1.16)	0.95* (1.11)	0.52* (0.92)	0.76* (1.02)	1.06* (1.22)	**2.00*** (1.48)
11	Living conditions	0.60 (0.92)	0.71 (1.14)	0.41* (0.90)	0.56 (1.15)	0.55 (1.05)	0.78 (1.24)	0.98* (1.37)
12	Problems with	0.95	0.77	0.52*	0.47*	0.52*	0.83	1.19

occupation	(1.0)	(1.12)	(0.94)	(0.95)	(0.92)	(1.18)	(1.43)
Total	15.70	12.16*	9.90*	9.01*	10.24*	13.32*	15.55
	(5.60)	(5.87)	(5.19)	(4.96)	(5.17)	(6.54)	(7.32)

Note: HoNOS = Health of Nation Outcome Scales, * $p < .0001$, clinically important elevations are bolded, because of the number of comparisons, t-values are not reported (can be acquired through the first author).

4.1.3 **Table 3**

Differences in Mean HoNOS Ratings Between Refugee Outpatients and Every Other Group and Corresponding 99% Confidence Intervals.

	HoNOS Item	Schizophrenia (F20-29) Diff. [99% CI]	Affective Disorders (F30-39) Diff. [99% CI]	All Anxiety Disorders (F40-49) Diff. [99% CI]	Personality Disorders (F60-69) Diff. [99% CI]	Addiction (F10-19) Diff. [99% CI]	Dementia (F00-09) Diff. [99% CI]
1	Overactive, aggression	.47 [.36 , .58]	.75 [.65 , .85]	.78 [.67 , .89]	.65 [0.53 , .78]	.51 [.38 , .64]	.05 [*ns*]
2	Non-acc. Self-injury	.12 [*ns*]	-.04 [*ns*]	-.33 [-.44 , -.22]	-.28 [-.41 , -.15]	-.13 [*ns*]	.22 [.11 , .33]
3	Drinking/ drug taking	-.52 [-.59 , -.44]	-.35 [-.42 , -.28]	-.43 [-.51 , -.35]	-.62 [-.73 , -.51]	-2.61 [-2.72 , -2.50]	-.22 [-.33 , -.11]
4	Cognitive problems	.84 [.74 , .94]	1.08 [.98 , 1.18]	1,31 [1.21 , 1.41]	1.24 [1.14 , 1.35]	.78 [.65 , .91]	-.54 [.70 , .38]
5	Physical illness	1.18 [1.06 , 1.30]	.91 [.78 , 1.04]	1.08 [.95 , 1.21]	1.14 [1.00 , 1.28]	.83 [.68 , .98]	0.16 [*ns*]
6	Hallucinations / delusions	-1.50 [-1.63 , -1.37]	.12 [*ns*]	.28 [.15 , .41]	.03 [*ns*]	-.13 [*ns*]	-.78 [-.96 , -.60]
7	Depressed mood	1.32 [1.21 , 1.43]	.33 [.22 , .44]	.72 [.61 , .83]	.78 [.66 , .90]	1.07 [.94 , 1.19]	1.27 [1.13 , 1.41]
8	Comorbidity/Anxiety	.81 [.69 , .93]	.94 [.82, 1.06]	.86 [.73 , .99]	.79 [.65 , .93]	1.03 [.89, 1.18]	.84 [.67 , 1.01]
9	Problems with relationships	.52 [.39 , .64]	1.06 [.94 , 1.18]	1.08 [.95 , 1.21]	.67 [.53, .81]	.83 [.68 , .98]	.44 [.26 , .62]
10	Problems with activities and…	.19 [.08 , .30]	.35 [.24 , .46]	.78 [.67 , .89]	.54 [.41 , .67]	.24 [.10 , .38]	-.70 [-.88 , -.52]
11	Living conditions	-.11 [*ns*]	.19 [.07, .31]	.04 [*ns*]	.05 [*ns*]	-.18 [*ns*]	-.38 [-.55 , -.21]

12	Problems with occupation	.18 [*ns*]	.43 [.31 , .56]	.48 [.35 , .61]	.43 [.29 , .57]	.12 [*ns*]	-.24 [-.43 , -.05]
Total		3.54 [2.83 , 4.25]	5.80 [5.10 , 6.49]	6.69 [5.97 , 7.41]	5.46 [4.69 , 6.23]	2.38 [1.53 , 3.23]	.15 [-.84 , 1.14]

Note. HONOS = Health of Nation Outcome Scales, Diff = difference, CI = Confidence Interval, *ns* = non-significant

4.1.4 **Table 4**

Effect Sizes (Cohen's d) of the Pre-treatment Differences on the HoNOS Between Refugee Outpatients and Every Other Group.

HoNOS item	Schizophrenia (F20-29)	Affective Disorders (F30-39)	All Anxiety Disorders (F40-49)	Personality Disorders (F60-69)	Addiction (F10-19)	Dementia (F00-09)
1 Overactive, aggression	.46	.92	.99	.75	.53	-
2 Non-accidental self-injury	-	-	-.28	-.28	-	.35
3 Problem-drinking /drug taking	-.48	-.38	-.46	-.62	-2.8	-.29
4 Cognitive problems	.86	1.3	1.9	1.7	.78	-.47
5 Physical illness	1.2	.82	1.0	1.2	.74	-
6 Hallucinations or delusions	-1.2	-	.34	-	-	-.65
7 Depressed mood	1.5	.31	.80	.88	1.2	1.4
8 Comorbidity/Anxiety	.75	.87	.80	.79	.94	.75
9 Problems with relationships	.42	.94	.96	.61	.73	.35
10 Problems with activities and daily living	-	.33	.87	.56	.22	-.56
11 Living conditions	-	.21	-	-	-	-.32
12 Problems with occupation	-	.45	.49	.45	-	-
Total	.60	1.1	1.31	1.0	.38	-

Note: HoNOS = Health of nation outcome Scales, effect sizes with minus in front indicate lower ratings of refugee outpatients than the reference group, "- " indicates non- significant differences.

4.1.5 **Table 5**

Percentage of Relative Improvement From Pre-treatment to Post-treatment on Each Domain of the Health of Nation Outcome Scales (HoNOS).

HoNOS item	Refugee Out-patients (n = 448)	Schizophrenia (F20-29) (n = 3175)	Affective Disorders (F30-39) (n = 3081)	All Anxiety Disorders (F40-49) (n = 1781)	Personality Disorders (F60-69) (n = 1030)	Addiction (F10-19) (n = 950)	Dementia (F00-09) (n = 656)
1 Overactive, aggression	18 %	65%	63%	62%	47%	69%	54%
2 Non-accidental self-injury	32 %	81%	83%	77%	71%	70%	74%
3 Problem-drinking or drug taking	0 %	45%	57%	45%	40%	36%	47%
4 Cognitive problems	11 %	31%	32%	35%	29%	34%	9%
5 Physical illness	0 %	17%	16%	22%	22%	24%	5%
6 Hallucinations or delusions	2 %	47%	69%	59%	57%	72%	49%
7 Depressed mood	18 %	53%	61%	53%	52%	54%	39%
8 Comorbidity/ Anxiety	10 %	47%	54%	46%	42%	49%	35%
9 Problems with relationships	14 %	23%	42%	32%	22%	26%	15%
10 Problems with activities and daily living	8 %	25%	40%	37%	25%	29%	5%
11 Living conditions	5 %	20%	30%	17%	16%	19%	9%
12 Problems with occupation	3 %	24%	30%	23%	11%	21%	10%
Total	10 %	39%	49%	44%	38%	40%	23%

4.1.6 References

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4.2 Article 4: Rasch Validation and Cross-validation of the Health of Nation Outcome Scales (HoNOS) for Purposes of Monitoring of Traumatized Refugees in Western Psychiatric Care

Sabina Palic MSc Psychology, Danish National Centre for Psychotraumatology, University of Southern Denmark, Campusvej 55, 5230 Odense M, Denmark,

spalic@health.sdu.dk

Michelle Lind Kappel MSc Psychology, Clinic for PTSD and Transcultural Psychiatry, Aarhus University Hospital, Skejbygårdsvej 13-17, 8240 Risskov, Denmark,

micpeder@rm.dk

Guido Makransky MSc Psychology, Ph.D., Department of Psychology, University of Southern Denmark, Campusvej 55, 5230 Odense M, Denmark,

gmakransky@health.sdu.dk.

Abstract

Background: There are currently no validated measures for monitoring of global psychiatric impairment in traumatized refugees in psychiatric care. The main challenges to validity are the high diversity of the refugees' symptoms, the requirements of stable measurement across many different cultures, and the use of interpretation in refugee treatment settings. Aims of the present study are to assess the psychometric properties of the Health of Nation Outcome Scales (HoNOS) in treatment seeking refugees in the West, and illustrate the utility of Rasch analysis in meeting the challenges of valid measurement in clinical refugee populations in the West.

Method: The psychometric properties of the HoNOS were evaluated using Rasch analysis of pre-treatment data from 448 consecutive traumatized refugee patients in Danish psychiatric clinics. Thereafter, a cross-validation of the pre-treatment HoNOS model was carried out on post-treatment data. Possible bias related to culture, need for translation, and gender were tested with Differential Item Functioning (DIF).

Results: A revised 10-item HoNOS fit the Rasch model at pre-treatment. This model also had excellent fit within the cross-validation data. Culture, gender, and need for translation did not exert serious bias on the measure's performance. Collapsing of disordered thresholds helped target the HoNOS to the clinical refugee population while maintaining the properties of a broad, global psychiatric measure.

Conclusions: The results of Rasch analysis demonstrated that the HoNOS is a valid and suitable, unidimensional measure of global psychiatric impairment in traumatized refugees. The property of unidimensionality is likely associated with the overall high level of impairment in this population. Sound measurement of global psychiatric outcomes in the highly complex refugee treatment setting is a prerequisite for everyday work. It is also a

prerequisite for stronger clinical studies shedding light on prognosis and needs of this highly vulnerable group of psychiatric patients in Western countries.

Keywords: refugees, HoNOS, impairment, validity, Rasch analysis

Introduction

Traumatized refugees in Western countries often have diverse psychiatric problems, the most common being posttraumatic stress disorder (PTSD), anxiety, and depression [1]. In addition, traumatized refugees often have other complaints such as chronic pain, social isolation, cognitive impairment, psychosis-like symptoms, as well as problems regarding family and occupational roles [2-5]. However, global psychiatric impairment in refugees is very difficult to document as there are currently no validated global measures of psychological and social impairment for this population [6]. Moreover, due to issues regarding validity, there appears to be no consensus regarding the clinical appropriateness of measures of global psychiatric impairment in the group. This leads to extensive problems in the monitoring of treatment progress and identification of appropriate treatment goals in treatment seeking traumatized refugees in the West. It also leads to the ineffective utilization of psychiatric and social services as provision of services cannot be matched to the need for help (impairment level) in a consistent manner. This type of practice comes with a high price for society, and an even higher price for affected individuals.

With regards to psychometric methodology, sound measurement of global psychiatric impairment in traumatized refugees is complicated by the presence of many diverse symptoms and social problems, which are difficult to capture by just one measure. Furthermore, the measures have to be short, and easy to apply, because the need for translation often doubles the assessment time in clinical refugee settings. Moreover, the use of the same measure for patients from many different cultural backgrounds, often results in insecurities with the clinicians about the appropriateness of the measure. Since their performance is heavily doubted, global measures of psychiatric impairment are seldom embraced by clinicians, even though measurement of global impairment has important clinical and societal implications for refugee patients.

The Health of Nation Outcome Scales (HoNOS) is an instrument used for routine treatment monitoring in psychiatry, which has good concurrent, content, and predictive validity as well as adequate inter-rater validity and sensitivity to change [7]. It is widely used in Western countries, and a Danish translation has been validated [8]. However, regarding the internal structure of the HoNOS, a number of competing factor structures have been suggested [7]. In addition, Rasch analyses of the HoNOS indicate a lack of unidimesnionality of a higher order construct of global psychiatric impairment in Italian psychiatric populations [9, 10]. On the other hand, the HoNOS has obvious appeal in refugee treatment settings: being a broad psychiatric measure, it is able to encompass the many problems of the traumatized refugees. Because it is an observer rated measure, it does not have to be translated into the many refugee languages. Not the least, as a routine measure, it is meant to be short and easy to apply.

The goal of this study is to assess the quality of the HoNOS as a monitoring tool for traumatized, treatment-seeking refugees in Denmark using Rasch analysis. Furthermore, the goal is to demonstrate how Rasch analysis lends itself to the validation of measures in highly complex refugee treatment settings by enabling analysis of factors uniquely associated with it. Thus, this study will also examine the influence of *cultural diversity* and *need for interpretation* in relation to the psychometric performance of the HoNOS in treatment seeking refugees in psychiatric care.

Method

Participants and procedures

A total of 448 patients from 3 departments (Aarhus, Horsens, and Randers) in a Clinic for Posttraumatic Stress Disorder (PTSD) and Transcultural Psychiatry (CPTP), Aarhus University Hospital (Denmark), were included in the study. CPTP is a specialized

service within the psychiatric services of the Danish mental health system. It covers the catchment area of the second largest city, 2-3 smaller towns, and the surrounding rural areas. Individuals are referred to CPTP on the suspicion of refugee, trauma- related psychiatric problems of diverse kinds. Furthermore, all individuals must fulfill the diagnostic criteria for one or more of the following ICD-10 [11] diagnoses: "Depressive disorders" (F32-34): "Neurotic, stress-related and somatoform disorders" (F40-49) – most often PTSD (F43.1): and "Enduring personality change after catastrophic experience" (F62.0). Individuals who have a primary diagnosis for a psychotic disorder and severe substance abuse are not a part of the CPTP's target group and are referred to other treatments. Comorbidity with other psychiatric disorders is however not systematically assessed at CPTP.

Data collection began in May, 2009 and continued until April, 2012. All patients who started and finished treatment during this 3-year period were eligible as participants for this study. The HoNOS was used to assess patients at two time-points: pre-treatment and post-treatment. The measure was administered by 11 different psychologists. The same psychologist rated the measure at both time points. Demographic information was collected during the initial interview. The study was approved according to the Århus University Hospital's ethical rules for analysis of data collected as a part of the treatment. Informed consent from the patients is not asked in Denmark, when treatment data are routinely collected and retrospectively analyzed for research purposes.

Measures

The HoNOS is a 12-item, observer-rated scale designed to reflect psychological symptoms as well as behavioral, organic, and social problems in psychiatric patients [12]. It is scored on a scale from 0-4, where higher values indicate higher impairment. In theory, the total score reflects the level of global psychiatric impairment. A validated, Danish version of

the HoNOS [8] was applied in this study. Ordinarily, the HoNOS should be rated soon after the first patient contact, however, the specific point of first assessment and subsequent monitoring frequency are dependent on the treatment setting. In the present study, the psychologists were allowed up to 4 sessions (including the initial assessment session) with the patient before having to rate the pre-treatment HoNOS. This was deemed necessary in the refugee treatment setting as *the need for translation* reduces the amount of information that can be conveyed during a single session (approximately by half). Furthermore, the patient and the psychologist have to spend some time together, so that the psychologist can appraise *the impact of cultural differences* between the rater and the patient.

Data analysis

The Rasch model

The Rasch model [13] is part of the framework of Item Response Theory (IRT) [14] and describes the association between a person's level of an underlying trait (e.g. general psychiatric impairment) and the probability of a specific item response on a measure of that trait. This association places the individual level of the underlying trait and the item difficulty of a specific measure on the same metric. Observed data are tested against the assumptions of the Rasch model, and if the assumptions are met, the raw score of a scale can be said to reflect the severity of that underlying trait. In psychiatry, this permits the direct interpretation of test scores as ratings of severity as well as a more precise monitoring of patients than that which is possible when using measures built upon the assumptions of classical test theory [15]. An extension of the Rasch model to items with more than two response options (polytomous items), the partial credit model [16], was applied in the study. There are three fundamental evaluation criteria associated with Rasch models: unidimensionality, item fit, and item invariance. General fit statistics are often reported in addition to these.

General model fit statistics

The most common general fit statistic reported in Rasch analyses is the chi square statistic, which reflects the property of invariance across the trait. The property of invariance requires that all items differentiate equally well in relation to different levels of the underlying trait. This is a necessary condition for the summation of item scores to an interval level total score. A significant chi square violates the requirements of the Rasch model because it indicates that the hierarchical ordering of the items varies across the trait. Item-person interaction statistics are often also reported. These statistics are transformed into a z-score, which represents the standardized normal distribution. Thus, when items and persons fit the Rasch model, a mean of approximately zero and a standard deviation of one are expected. A significance value of 0.05, with a Bonferroni adjustment to account for the number of hypotheses tested, was used in this study.

Unidimensionality

A fundamental assumption of the Rasch model is unidimensionality, which implies that the items of a scale measure a single underlying construct. One way of testing the unidimesnionality assumption is by testing for the local independence of the items [17]. Item dependency occurs when items are redundant or linked in some way such that the response on one item determines the response on another. Thus, local independence implies that there should be no further associations between items other than random associations once the Rasch factor (i.e. the underlying trait) has been taken into consideration. Local dependence is assessed using the residual correlation matrix. Items with residuals over 0.2 are typically labeled as being locally dependent. A formal test of unidimensionality [18] was also used in the study. This test uses the first residual factor in a principal components analysis (of

residuals) to determine two groups of items; those with positive- and those with negative loadings. Each set of items is then used to make an estimate for each person in the sample (e.g. estimate of general psychiatric impairment). Given that the items form a unidimensional scale, it is expected that there should not be much difference between the person estimates from the two item subsets. An independent samples t-test is used to determine whether there is a significant difference between the two estimates. This was repeated for each person with the expectation that the percentage of tests lying outside the range of -1.96 to 1.96 should not exceed 5%. A confidence interval for the binomial test of proportions for the observed number of significant tests was also applied. If the value does not overlap the 5% expected value then the scale is said to be unidimensional.

Item fit

Item fit is concerned with whether or not items fit the unidimensional Rasch model. A commonly used method for assessing item fit is the chi-square statistic. The chi-square statistic compares the difference between observed values and expected values for groups representing different severity levels (class intervals) across the trait being measured (general psychiatric impairment). Residuals in the range of ±2.5 indicate a good fit whereas significant chi square statistics indicate a misfit.

Item invariance

Item invariance requires that item estimation be independent of the subgroups of individuals completing the measure. In other words, item parameters have to be invariant across populations [19]. Items that do not demonstrate invariance are commonly referred to as exhibiting differential item functioning (DIF). DIF occurs when different subgroups of individuals within a sample (e.g. persons with different cultural backgrounds) have different

scores on specific items despite there being equal levels of impairment on the underlying trait. The presence of DIF is detected through the analysis of variance of item scores across each level of the person factor (e.g. cultural background) and is indicated by a significant main effect of the person factor.

In addition to these three criteria, inappropriate category ordering i.e. disordering of thresholds was assessed. Optimally, each response option for each item should correspond to a distinct portion of the impairment continuum. Disordering of thresholds occurs when certain response options are not endorsed well or when response options are difficult to differentiate from one another. Disordering of thresholds can be solved by collapsing or recoding redundant categories. It is important, particularly in clinical practice, that measures are appropriately targeted to assessment populations. Poorly targeted measures often result in floor or ceiling effects. Well targeted measures have a mean person location score close to zero, which represents the mean location of the items. Negative mean person locations indicate that the group has a lower level of general psychiatric impairment than the mean of the scale whereas positive mean person locations indicate the opposite. Reliability is assessed using a Person Separation Index (PSI) as well as Cronbach's alpha (with a similar interpretation for the two measures).

Rasch analysis of the HoNOS data

The highest percentage of missing data at the variable level was 16%. Little's MCAR test indicated that the data were missing completely at random. Missing data were imputed in SPSS 20.0 using the EM algorithm [20]. Data were then fitted to the Rasch model using RUMM2030 software [21]. As regards to the pre-treatment data, items with disordered thresholds were re-coded into appropriate categories and the general fit of the data was then assessed. Revisions were made to the pre-treatment data in order to obtain a scale that fitted

the Rasch model. The post-treatment data were used to cross-validate the fit of the revised HoNOS in order to determine whether it had the same psychometric properties at post-treatment than at pre-treatment. Stabile psychometric properties at pre-treatment and post-treatment indicate good treatment monitoring properties. The impact of *cultural diversity* on the measure's performance was assessed by dividing the patients into two large cultural subgroups, the "Middle East" (65.2% = Iraq, Iran, Lebanon, Jordan, Syria, Kuwait, Yemen, Afghanistan) and the Balkans (25.8% = Bosnia & Herzegovina, Kosovo, Serbia, Montenegro, Macedonia, Croatia), as well as an additional, smaller heterogeneous group (8.9% = Somalia, Sri-Lanka, Indonesia, Congo, Vietnam, Ethiopia, Georgia, Colombia).

Results

Approximately 93% of all eligible patients were included in the study. Of these 45.5% were female, 38.6% had at least 10 years of formal education, 12.1% had 1-5 years of education, and 8.5% had no education. Pertaining to exposure to severe war trauma, 31.3% reported having been tortured, and 35.7% reported imprisonment (not mutually exclusive). The mean length of resettlement time in Denmark at the start of treatment was 12.5 years (SD = 6.4, range: 0-29 years) - 63.4% used an interpreter. The mean HoNOS score at pre-treatment was 15.7 (SD = 5.6), indicating very high levels of global psychiatric impairment in this sample. Items 1, 3, 6, 8 and 11 had disordered thresholds and were collapsed before the initial Rasch analysis (see Appendix 1 for details).

Initial fit of the HoNOS to the Rach model

The initial analysis of the fit of the pre-treatment data to the Rasch model showed a significant item–trait interaction. This suggests some misfit between the data and the model. The residual mean value for the items was -0.10 (*SD* = 1.9). The residual mean

value for persons was -0.22 (*SD* = 0.84). This indicates no serious misfit between the participants in this sample and the model. Lack of invariance of item difficulty across the scale was indicated by a significant chi square value (x^2 = 155.04 (*df* = 60), $p < .00001$). As regards to reliability, the PSI statistic and Cronbach's alpha were both 0.78. This indicates acceptable person separation and internal consistency reliability of the HoNOS. The fit of the individual items revealed that item 5 (*physical illness*) and item 10 (*problems with activities of daily living*) deviated significantly from the partial credit Rasch model (see column 3 in Table 1). The positive fit residual value for item 5 suggested low levels of discrimination. The content of item 5 (*physical illness*) is not necessarily central to the theoretical construct of general impairment due to psychiatric illness and was, therefore, eliminated from the scale in order to assess whether a measure that fitted the Rasch model could be obtained. The negative fit residual value for item 10 (*Problems with activities of daily living*) suggested that this item had higher levels of discrimination than the scale's remaining items. A possible source of deviation could be local dependence or multidimensionality. An analysis of the residuals between item 10 and the remaining items did not indicate any local dependence. However, the content of item 10 suggests that this item is quite broad, which could mean that clinicians use it as a general summary item. In order to fit the data to the model, item 10 was removed from the scale (the implications of this are addressed in the discussion section). Furthermore, item 2 (*non-accidental self-injury*) had a significant chi-square value. However, the residual value of the item did not indicate any problems with over- or under discrimination. Due to repeated hypothesis testing, a significant chi-square for item 2 may have been caused by chance. Therefore, Item 2 was retained in the revised version of the HoNOS. The results from follow-up analyses indicated that the item fit the Rasch model (see columns 5 through 8 in Table 1).

Fit of the 10-item HoNOS to the Rach model in the pre-treatment data

The revised, 10-item HoNOS fit the Rasch model in the pre-test sample. The residual mean value was -0.29 (*SD* = 0.88) and -0.24 (*SD* = 0.74) for items and persons, respectively. There was also a non-significant chi squared interaction (x^2 = 73.39 (df = 50), p < .0173), which indicates invariance of item difficulty across the scale. In addition, all 10 items of the revised HoNOS had appropriate fit with non-significant residuals (columns four and five in Table 1). The average mean person location value of -1.25 suggests that patients had a slightly lower level of general psychiatric impairment than the average of the scale items. Significant positive local dependence was found only between item 11 (*problems with living conditions*) and item 12 (*problems with occupation and activities*), which indicates that these items have a higher correlation than what is expected by the Rasch model.

The unidimensionality test [18] of the revised, 10-item HoNOS resulted in 27 of 448 significant tests, with a confidence interval between 0.04 and 0.08. As this does not exceed the 5% level, the test failed to reject the unidimensionality assumption. The revision of the HoNOS resulted in a PSI statistic of 0.74 and a Cronbach's alpha of 0.73, indicating that it had retained acceptable person separation and internal consistency reliability. The 10-item HoNOS had DIF by gender on item 1 (aggressive behavior), f (1) = 16.60, p < 0.0005 and item 7 (*problems with depressed mood*) f (1) = 11.57, p < 0.0005, whereas item 12 (*problems with occupation*) had DIF by culture f (1) = 14.69, p < 0.0005. None of the items had significant DIF by translator. This revised version of the HoNOS, with a maximum total score of 32, was used in the remaining analyses and is referred to hereafter as the Refugee HoNOS.

Cross-validation: Assessing the fit of the Refugee HoNOS within the post-treatment data

It was important to carry out a cross-validation of the Refugee HoNOS in order to ensure that the suggested changes did not just represent empirical adjustments and that the measure had retained its psychometric properties when re-tested in the same population *after* treatment. The cross-validation results provided excellent support for the validity of the refugee HoNOS. The residual mean value for items and persons was -0.46 (*SD* = 1.10) and -0.23 (*SD* = 0.66), respectively. There was also a non-significant chi squared interaction (x^2 = 82.50 (*df* = 90), *p* = .70), indicating invariance of item difficulty across the scale. All items apart from item 9 had appropriate fit at post-treatment. Item 9 had a slightly lower residual but not a significant chi squared value (see Table 1). The refugee HoNOS resulted in a PSI statistic and a Cronbach's alpha of 0.80. There was no local dependence with residual values over 0.2, indicating that the high local dependence found between items 11 and 12 at pre-test may be due to chance. The unidimensionality test resulted in 4.69% significant t-tests, which is below the 0.05 value. Significant DIF for cultural origin was found for item 7 (*problems with depressed mood*), *f* (1) = 11.84, *p* < 0.000, and item12 (*problems with occupation) f* (1) = 8.41, *p* < 0.001. Significant DIF for translator was found on item 2 (*non-accidental self - injury) f* (1) = 13.39, *p* < 0.0005 and item 4 (*cognitive problems*), *f* (1) = 13.67, *p* < 0.0005. No DIF was found across gender groups.

Discussion

Overall, the results of the present study provide support for the application of the refugee HoNOS as a measure of general psychiatric impairment in treatment-seeking, refugee populations in Denmark. They also demonstrate the utility of Rasch analysis in providing detailed and valuable information about the function of every item, the measure's overall targeting for the group, and its performance in complex clinical conditions requiring

cross cultural use and interpretation. The refugee HoNOS was found to be stable across different test points, which supports the construct validity and reliability of this measure. Furthermore, given that DIF was only found consistently across the measurement points on item 12 (*problems with occupation and daily activities*) the DIF on the remaining items could be coincidental. One possible explanation for why item 12 is dependent upon *amount of global psychiatric impairment* as well as *cultural origin* is that *educational level* and *labor market participation before resettlement* may play a role in clinicians' evaluations of occupational problems. Hence, individuals originating from countries that have a higher level of education and where women are more integrated in the labor market (e.g. the Balkans) are more likely to be judged by clinicians as having fewer occupational problems. We suggest that item 12 be retained in the refugee HoNOS as the evaluation of occupational problems is an important clinical aspect of general psychiatric impairment. Moreover, the item does not appear to threaten the overall validity of the measure. Clinicians should be aware of the possibility that this item can introduce some rater bias if there are large ethnic differences in the educational and work norms among patients. Raters can also be trained to assess this item more closely to the underlying dimension (i.e. focus on rating occupational problems only as a function of other problems on the HoNOS and try to disregard knowledge of education and prior work experience in their decision making).

Alongside the established construct validity and reliability for this measure, the results indicate that the refugee HoNOS has very good psychometric properties, and that it can be used for treatment monitoring in traumatized refugees. Although our validation of this measure was carried out on treatment-seeking, refugee patients in Denmark, the validation was estimated on a well-represented sample of consecutive patients from standard treatment facilities in the country. Therefore, it is likely that the psychometric properties of the refugee HoNOS can be generalized to refugee patients in the other parts of Denmark, and possibly in

other European countries given similar demographic compositions and chronification of symptoms (indicated by the long resettlement time before treatment seeking).

Considerations for clinical application of the refugee HoNOS

As regards to item 10 *(problems with activities and daily living*), the exclusion of an item with higher levels of discrimination seems counterintuitive from a clinical perspective, however, it makes good sense in terms of measurement paucity. Namely, if one were to assess general impairment due to psychiatric illness using only item 10, then this item would probably provide a good general picture of the construct. This is the reason why item 10 functions well alone but not in relation to the other items. The question that naturally arises now is '*why not use this item on its own to assess general psychiatric impairment?*' Measures preceding the HoNOS such as the Global Assessment of Functioning [22], which represent complex concepts such as general psychiatric impairment by using a single numerical indicator, cause problems regarding the reliability of scoring and have limited clinical utility [23]. Given that the remaining 10 items of the HoNOS all measure aspects of the same global construct; "*problems with activities and daily living (due to psychiatric illness)",* they actually create a more clinically meaningful profile of problematic areas of functioning. Thus, the evaluation of item 10 becomes clinically redundant, and, in terms of the Rasch model, it threatens the fit of the scale and hinders the summation of items to an interval level total severity score.

Although from a psychometric perspective item 5 (*physical illness or disability problems)* does not appear to fit the same dimension of general psychiatric impairment as the remaining 10 items of the HoNOS, assessment of physical problems is clinically relevant for many traumatized, refugee patients. The most plausible explanation for why this conceptually important item does not appear to fit psychometrically well with the other items is that

physical problems in this patient group require complex evaluation, which cannot be accomplished through the use of a single item. The causes of physical problems in refugee patients can be attributed to a number of different underlying mechanisms such as chronic pain from torture, ill health as a result of having had a strenuous life, psycho-somatic reactions as well as different combinations of these. Depending on the type of underlying mechanism, the relationship between item 5 and the remaining items of the HoNOS is likely to change resulting in unstable estimates of the underlying dimension of general physical impairment. Therefore, the evaluation of the refugee HoNOS can be supplemented by other more specific measures of physical impairment for patients with very salient physical problems.

The recoding of thresholds for some of the HoNOS items resulted in infrequently endorsed score options having to be collapsed into larger categories. The same pattern of collapsing was necessary at both pre- and post-treatment, which indicates that some parts of the original score continuum of the HoNOS have rarely been applied by clinicians in this population. Although it is possible that the scoring continuum may have been incorrectly applied by clinicians, this is not the most likely explanation as this study had eleven different raters who almost never applied certain categories. Therefore, the recoding of thresholds in the refugee HoNOS appears to have had the primary effect of accomplishing a better targeted measure of the level of global psychiatric impairment in this population. Furthermore, the recoding of thresholds in the refugee HoNOS improves the fit of the measure to the Rasch model and results in desirable psychometric properties. For the purposes of obtaining a more precise measurement and monitoring of refugees in psychiatric care, the 10-item HoNOS can be numerically re-scored according to Appendix 1.

Implications for the unidimensionality of the HoNOS measure

The 10-item HoNOS, which consists of 3 items for behavioral, 1 item for physical, 3 items for psychological and 3 items for social problems, was found to be unidimensional in the present sample. However, previous studies concerning the dimensionality of the HoNOS show that the HoNOS is not unidimensional in Italian psychiatric patients [9, 10]. One possible explanation for the dissimilarity between the present findings and those of previous studies is that the unidimensionality found in the current sample is present because of refugee patients' overall high problem profile on the HoNOS. Our study involving this same refugee sample indicates that the average ratings on the HoNOS are comparable to those of Danish inpatients, specifically addiction and dementia patients who have the highest HoNOS ratings (submitted). However, the total ratings of the refugees on the HoNOS (and most of the HoNOS' 12 impairment domains) are significantly higher than the ratings of large groups of Danish inpatients with affective, anxiety, and personality disorders as well as schizophrenia. The structure of the HoNOS in the Italian study may, therefore, be a reflection of the patient composition in the Italian psychiatric system. Patients with schizophrenia were overrepresented in both Italian samples [9, 10]. Hence, the HoNOS was psychometrically reduced to a measure of four social problems and problems with cognition and hallucinations [10]. Indeed, this is an item constellation that reflects the general representation of impairment regarding schizophrenia. The Italian studies also applied factor analytic approaches in order to test the dimensionality of the HoNOS, however, factor analysis is based on principles of correlation between items. Therefore, the clustering of items may reflect similar patterns of endorsement difficulty in the items of a scale rather than the underlying dimensionality [24]; in which case the "dimensionality" of the measure again becomes a reflection of the dominant problem areas in the population of interest.

The dimensionality of the 10-item HoNOS should be tested in other psychiatric populations with overall high problem profiles on the HoNOS. An example could be patients with double diagnoses whose addiction and psychiatric comorbidity create extensive behavioral and social problems. Another example could be patients with psychiatric problems due to severe childhood maltreatment. These patients usually also have overall high problem profiles that span across the areas of behavioral inhibition, psychiatric co-morbidity, and impaired social functioning due to compromised socio- emotional and physiological development in relation to severe early trauma. Furthermore, early childhood maltreatment and trauma are known risk factors for many psychiatric diagnoses and are rather prevalent in psychiatric patients [25].

Finally, the collapsing of infrequently used score options could be used as a way of establishing a broader application of the 10-item HoNOS as a sound measure of general psychiatric impairment in different psychiatric populations. The original 12-item HoNOS is conceptually intended to evaluate the typical areas of concern for psychiatric patients. Although they are all clinically relevant in relation to psychiatric impairment, the levels of impairment on specific items will probably vary as a consequence of the patients' diagnoses. Therefore, in measures of complex global constructs, the recoding of items into appropriate categories allows for the better targeting of measures to specific diagnostic populations whilst retaining sound measurement of global problem areas, which are important outcomes in psychiatry. If the 10-item HoNOS can be applied to other psychiatric populations with overall high problem profiles, this may lead to the development of other versions of the 10-item HoNOS that have different re-scoring algorithms for different primary diagnoses.

Limitations

As this study was of naturalistic design, data were collected as a part of the standard evaluation of the CPTP's services and inter-rater agreement was, therefore, not established. However, the psychometric stability of the measure, which is demonstrated in this study, could represent an indirect indicator of relatively consistent ratings. It would have been hard to establish psychometric stability had the 11 different raters been making very different evaluations. Other validity criteria including the clinical utility of the HoNOS and the differentiation of HoNOS profiles from those of other psychiatric patients for the same sample are presented in a different study (work in progress). The small size of the heterogeneous group in the DIF analysis of cultural origin probably means that it is difficult to detect a possible cultural bias of this group on the refugee HoNOS. Claims of the measure's cultural stability are, therefore, best substantiated in the two larger cultural groupings. Future studies should also examine the overall clinical utility of the refugee HoNOS in relation to its ability to predict service utilization and long-term outcomes.

Conclusions

The refugee HoNOS is a sound measure for monitoring of global psychiatric impairment in refugees in Western psychiatric care. As indicated in this study, the majority of the participants had been resettled in Denmark for over a decade. Therefore, it is more correct to characterize the participants in this sample as former refugees (they were interacting with different social and health professionals in Denmark on the same level as other Danish patients). Thus, the sound assessment of global psychiatric impairment appears to be important for appropriate service utilization and the overall protection of this highly vulnerable psychiatric population. Rasch analysis lends itself well to validation of measures in highly complex clinical settings, such as clinics for traumatized refugees in Western

countries. There are also obvious benefits of applying DIF analysis in Rasch models for testing the translation equivalence of self-report measures in refugee settings. Better validated measures, known to have robust performance in refugee settings are also a prerequisite for better clinical studies, and informed decisions on behalf of this patient group.

4.2.1 **Table 1**

Overview of Item Fit in the Three Analyses.

		Original HoNOS		10- item HoNOS in pre-test		10-item HoNOS in post-test	
		Fit residual	**Chi squared Probability**	**Fit residual**	**Chi squared Probability**	**Fit residual**	**Chi squared Probability**
Item01	Overactive, aggressive...	1.07	0.86	0.67	0.40	-0.79	0.63
Item02	Non-accidental self-injury	0.92	< **0.005**	0.21	0.03	-0.09	0.47
Item03	Problem drinking or drug taking	0.40	0.34	0.22	0.24	-0.34	0.70
Item04	Cognitive problems	-1.56	0.10	-1.24	0.37	-0.20	0.26
Item05	Physical illness or disability problems	4.13	< **0.005**				
Item06	Problems with hallucinations and delusions	-1.83	0.17	-1.80	0.03	-1.07	0.26
Item07	Problems with depressed mood	0.84	0.40	0.58	0.42	-0.12	0.98
Item08	Other mental and behavioral problems	0.68	0.19	0.64	0.14	0.93	0.53
Item09	Problems with relationships	-1.08	0.41	-1.09	0.64	-2.91	0.17
Item10	Problems with activities of daily living	-3.44	< **0.005**				
Item11	Problems with living conditions	-0.66	0.33	-0.63	0.18	0.94	0.66
Item12	Problems with occupation and activities	-0.65	0.17	-0.53	0.23	-0.95	0.53

Note. Bolded values represent significant deviations from the model expectations after Bonferroni adjustments for multiple testing.

4.2.2 **Appendix 1**

Instructions for rescoring of the refugee HoNOS

1. Rescore the items following these instructions:

Item 1	*Overactive, aggressive behavior*	If scored 3 rescore into 2 4 rescore into 2	Range of item 0-2
Item 2	*Non-accidental self-injury*	-	0-4
Item 3	*Problem drinking or drug taking*	If scored 1 rescore into 0 2 rescore into 1 3 rescore into 2 4 rescore into 2	0-2
Item 4	*Cognitive problems*	-	0-4
Item 6	*Problems with hallucinations and delusions*	If scored 2 rescore into 1 3 rescore into 2 4 rescore into 3	0-3
Item 7	*Problems with depressed mood*	-	0-4
Item 8	*Other mental and behavioral problems*	If scored 1 rescore into 0 2 rescore into 0 3 rescore into 1 4 rescore into 2	0-2
Item 9	*Problems with relationships*	-	0-4
Item 11	*Problems with living conditions*	If scored 3 rescore into 2 4 rescore into 3	0-3
Item 12	*Problems with occupation and activities*	-	0-4

2. Where no rescoring is indicated, items should retain the original scoring continuum.

3. Sum up the scores for all 10 items.

4. The range of the refugee HoNOS is 0-32.

4.2.3 References

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5 Chapter 5: General Discussion

This chapter summarizes the main findings from the DESNOS and the HoNOS empirical studies. Furthermore the limitations and implications of the four articles will be discussed in terms of future research. The thesis was overall explorative including both clinical and psychometric objectives. The clinical objectives focused on the *description* of symptoms and the psychometric objectives focused on the *development* of measurement of complex traumatization in the clinical practice with traumatized refugees.

5.1 Major findings

Major *clinical* findings from the present studies were that:

- DESNOS resembled PD in Bosnian refugees (article 1).
- DESNOS and PD were present to the same degree in Bosnian refugees who do not have a history of childhood maltreatment as in those who do (article 1).
- Pathological dissociation was prevalent in Bosnian treatment seeking refugees (article 2).
- The level of global psychiatric impairment in traumatized treatment seeking refugees was higher than in most groups of Danish inpatients (article 3).
- The profile of global psychiatric impairment in traumatized refugees was diverse and did not resemble any of the impairment profiles of the well-diagnosed groups of psychiatric inpatients (article 3).

Major *psychometric* findings from the present studies were:

- Global, diverse psychiatric impairment in traumatized refugees can be reliably measured and monitored (article 4).

- Furthermore, the underlying structure of the diverse, global psychiatric impairment in the traumatized refugees was unidimensional (article 4).

Overall, a number of *clinical* findings related to the character and the diversity of symptoms of complex traumatization in traumatized refugees were made. Furthermore, the HoNOS study indicated that complex psychiatric concepts can be reliably measured on a general level in culturally diverse groups of traumatized refugees. Further research is recommended in the area of the resemblance of complex traumatization in refugees with PD. In addition, further exploration of psychiatric comorbidity related to the diverse global psychiatric impairment on the HoNOS is recommended. The documentation of complex traumatization in refugees as *one* well-demarcated syndrome requires additional development and validation. This development is dependent on further improvement in the measurement of *multifaceted* psychiatric concepts in traumatized refugees, extending beyond factors associated with PTSD, anxiety and depression. The general limitations of the studies and recommendations for future research are discussed below.

5.2 The challenge of representative, large samples in clinical studies of refugees

The most important limitation of the DESNOS study was the low participation rate in the sample of Bosnian refugees. As explained in articles 1 & 2 this limits the generalization of the results to only the higher functioning Bosnian treatment seeking refugees. In comparison to previous studies, the current study included a larger sample however, this was still not large enough to allow for factor analytical work to be carried out. The underlying structure of DESNOS symptoms in traumatized refugees therefore, requires further research attention using larger sample sizes.

The existing studies testify to the fact that problems with unrepresentative and small sample sizes are still a challenge in the study of traumatization within clinical refugee samples. With regards to the present study, the limitations must be considered in light of the limited resources of a doctoral project in the rather complex, poorly developed field of refugee trauma studies. Specifically, the challenge of this study was in the recruitment of highly vulnerable refugee patients. Volunteering to participate in a project in which assessment is undertaken by unknown individuals, who were not members of staff in rehabilitation clinics, made recruitment difficult. This difficulty was expected and considered in terms of the overall high level of impairment - particularly in light of the high levels of isolation and mistrust towards other people which were evident for this patient group (study 1). Therefore, in order to access a large homogeneous clinical refugee group by non-staff members, more time would be needed for the data collection process than designed by the present doctoral study. Future studies attempting to sample large groups of treatment seeking refugees in western clinics by researchers outside the clinics should consider a much longer period of data collection. This consideration may resolve the problems with small sample sizes but not necessarily problems associated with the representative nature of the sample.

A much better option in terms of representativity and demands on the patients is represented by the routine collection of treatment data in the HoNOS studies. The most obvious solution to the problem of small sample sizes in clinical refugee studies and especially in terms of generating a more representative sample would be to integrate clinical and research practices in the Western refugee clinics. In-house studies would result in less psychological strain on the patients, because they will have a better opportunity to develop a trusting relationship with the staff. In Danish clinics human and economic research resources for traumatized refugees are currently very limited and focus predominantly on treatment. Most Danish clinics for the treatment of traumatized refugees consequently do not employ

researchers and have limited or no economic resources besides those for treatment activities. If better clinical studies of traumatized refugees in the West are to be made research funding for refugee rehabilitation clinics is much needed. From a social perspective, the integration of research and clinical practice in the work with traumatized refugees is both desirable and necessary. As has been argued, research in modern western societies is a social means of *validating* the impairment in traumatized refugees as well as *validating* the related clinical practice.

5.3 Methodological concerns in the HoNOS study

The HoNOS study included a more representative sample than the DESNOS study. However, it was undertaken for purposes of routine treatment evaluation, which has other methodological limitations. One limitation was the lack of examination of inter-rater agreement on the HoNOS. Established inter-rater agreement on the HoNOS may have permitted stronger conclusions from the findings. Furthermore, knowledge of the diagnostic status and patterns of psychiatric comorbidity in the refugees would have been valuable in better understanding the profile of global impairment on the HoNOS. Finally, the clinical utility of the HoNOS in refugee samples needs to be examined further, especially with regards to its predictive validity and long term outcomes.

The limitation of the HoNOS study in relation to complex PTSD is that the material was retrospectively used for research purposes, and therefore not intended from the outset for the study of complex PTSD. HoNOS in itself does not measure "complex PTSD". It measures global impairment in psychiatric patients. As such, the results only document the diverse nature of symptoms, and the very high level of global impairment in treatment seeking traumatized refugees in the West. It cannot, therefore be concluded from the HoNOS data whether these individuals had DESNOS. Moreover, whether the "complex" profile of

impairment on the HoNOS is related to an underlying complex PTSD syndrome or is better explained by presence of other mental disorders cannot be deduced from the present studies. However, it is difficult to argue against the notion, that the overall high impairment profile of the traumatized refugees on the HoNOS is clinically "complex"- especially when it is compared to that of other psychiatric patients with recognized psychiatric diagnoses. Furthermore, the unidimensionallity of the HoNOS indicates that the diverse psychiatric and social problems in the refugees are co-occurring to such a degree that they can be considered as indications of one underlying phenomenon. Future studies, documenting the association between complex PTSD and the overall-high refugee HoNOS profile are needed.

Finally, routine treatment evaluation does not necessarily make good research (it can, when it is purposefully planned, document scientifically interesting aspects of the clinical practice). In most instances, results of routine clinical evaluations do not contribute to scientific knowledge because the process is not controlled to a sufficient degree to provide answers to fundamental questions in a given research field (e.g. failure to control pertinent factors like inter-rater reliability and psychiatric comorbidity in the present HoNOS study). Despite this, the present HoNOS data contributes to the literature by providing data on the level of global psychiatric impairment in a *representative* group of treatment seeking traumatized refugees in a Western clinic that has never been documented before. The reported clinical norms and the development of a psychometrically reliable Refugee HoNOS make an important contribution to the measurement of trauma-related impairment in refugees. The findings thus contribute to the efforts of documenting and reliably measuring the *diversity* and *severity* of *trauma-related* impairment in refugees.

5.4 Cross-cultural issues in psychometrics

Many problems related to cross-cultural measurement of psychiatric constructs were circumvented in the culturally mixed HoNOS study because the HoNOS is an observer rated measure. Hence, the HoNOS was not translated to the languages of the respective refugee groups. Also, the question of cross-cultural universality of HoNOS items lies with the clinician when the measure is observer rated. Therefore, the evaluation of the cultural bias related to the Refugee HoNOS (which was tested in the Rasch model in article 4), pertained to the clinicians' evaluation of the cross-cultural equivalence. That is, we tested whether the clinicians were rating the HoNOS items in the same way irrespective of the patients' cultural origin. Despite the specific example to which Rasch analysis was applied in this thesis, the psychometric tradition of Item Response Theory (IRT) has important implications for cross-cultural measurement of psychiatric phenomena. Namely, psychometric models based on IRT focus on the function of each specific item in a measure (as well as their relationship with the underlying construct)[86]. IRT methods therefore allow for identification of specific items which have a problematic function in different subgroups of refugees based on statistical calculation. It is not possible to identify with IRT models whether the problem in Differential Item Functioning (DIF) is related to the inadequate translation or lack of cultural universality of a particular item. This refinement process is left to the researcher who can identify which items may be problematic using statistical procedures. The researcher can then make hypothesis about reasons for an item's inadequate functioning and test new item formulations in new samples.

DIF analysis is a logical technique within the Rasch model which also requires that 1) the measure is unidimensional, 2) that each item measures the underlying dimension equally well, 3) that each item score increases with the increasing of the underlying dimension and 4) that each item score corresponds to a distinct portion of the continuum of

the underlying dimension. Therefore, if the requirements of the Rasch model are met, DIF for a particular item is more likely to be related to the cultural origin of the participants than to other measurement problems. However, the application of the Rasch measurement model has only recently been recognized in studies of health related outcomes[93]. Furthermore, the wider use of this method is hindered as the current software for its application requires higher skills than most widely used statistical programs in social sciences. Therefore, the wide use of the Rasch measurement model in refugee research may not be applied in the near future. Until Rasch analysis becomes more available to the researchers, it is important to keep in mind that DIF analysis is in principle just an analysis of variance (ANOVA), with the items scores as the dependent variable and the cultural refugee subgroups as the independent variable. Hence DIF can also be tested with a number of easily accessible techniques like t-tests, ANOVA, and logistic regression analysis. DIF analysis within these methods is not as rigorous as within the Rasch model (other underlying measurement problems cannot be excluded when DIF is indicated by these alternative methods). However, this is a simple way of empirically testing whether function of items could be compromised by the cultural heterogeneity of a sample and if the different refugee subgroups can be pooled in a subsequent statistical procedure. Also, there is no reason why an analysis of variance should not be performed before or after a factor analysis to test the possible influence of the cultural heterogeneity of a given sample on the identified dimension and its items. Wider use of the Rasch measurement model for purposes of reliable and valid cross-cultural measurement is to be preferred in future studies. However, general ideas about explicitly testing for sources of item variance can be borrowed from IRT and applied to cross-cultural measurement. Thus, more attempts should be made in general to test the influence of cultural heterogeneity on the applied measures with whichever method is available to the researcher of refugee trauma.

5.5 Other methodological considerations in future research

Future research of complex PTSD in refugees also needs to consider the longevity of the impairment which is proposed in relation to complex traumatization. Cross sectional studies of syndromes which are purported to be of long duration cannot inform us about the developmental course of chronic disorders. Longitudinal studies of complex PTSD (as well as PTSD) are needed in treatment seeking refugees. Research is limited in the processes by which complex PTSD develops in adults who were not exposed to childhood maltreatment. Importantly, little is known about the longitudinal course of PTSD. The currently used labels of delayed and chronic PTSD are rather arbitrary from a scientific point of view [94]. Therefore, more research is needed to answer when and how "simple" PTSD becomes a chronic trauma adaptation like complex PTSD. Some of the current leading studies, in this respect, have been conducted on Israeli ex-Prisoners of War (POWs) [95-98]. In these studies psychiatric morbidity was measured over a period of 35 years and compared to a control group of Israeli soldiers from the same war who were not exposed to imprisonment and torture. Consecutive studies of Israeli ex-POWs have shown that they have had frequent "delayed" as well as "reactivated" PTSD over the 35 years [98] (i.e. their state was best characterized by periodic absence of symptoms). Moreover, a large number of diverse symptoms of psychiatric illness, not always co-occurring with PTSD, were present in the POWs and the related impairment was more treatment resistant than in the control group [97]. Pertaining to personality function, the POWs were more insecurely attached than their counterparts, despite the fact that they constituted a representative sample of the background population, when screened before military service. Furthermore, following repeated measurement, findings indicated that the POWs were becoming more insecurely attached as they got older [96]. This was contrary to the control group and in general contrast to the human experience. Due to natural maturation, individuals tend to get more securely attached

over the years [96]. As attachment disturbances are closely related to the development of personality disorders and interpersonal dysfunction [99], this Israeli study may be the first to show the *mechanism* behind trauma-related personality *change*. Thus, in the treatment seeking traumatized refugees who also constitute a group with high prevalence of imprisonment and torture as well as exposure to very diverse trauma of long duration, the most likely duration and course of trauma-related impairment needs to be scientifically *documented*. Finally, another valid area of research regarding the refugee experience would be to study how resettlement challenges and socio-cultural factors interact with the psychiatric impairment in the process of adaptation to extreme trauma.

5.6 Conclusions

This thesis has shown that the study of complex traumatization in refugees is generally a neglected field of research. This may be attributed to the complexity of the area. In terms of the complex social validation processes, complex symptom presentations and the complexity of cross-cultural measurement, the refugee clinics have much to gain by future well-planned research studies. This thesis demonstrates that development of sound measurement of complex psychiatric phenomena in refugees is possible and that new statistical methods are beneficial to the measurement of cross-cultural issues. The thesis also demonstrates that the treatment seeking refugees in Denmark have complex and diverse psychiatric symptoms and a very high level of global impairment. Developments related to further measurement, documentation and treatment of this impairment are much needed. Monitoring of only PTSD, anxiety, and depression in treatment seeking refugees is probably insufficient for the purposes of systematic treatment implementation. This thesis further stresses the importance of social *validation* of *extensiveness* of refugee trauma. As the history of concepts of psychological trauma repeatedly demonstrates, wide spread social recognition of impairment is a prerequisite for adequate actions on behalf of society. Considering the

numbers of refugees, political prisoners and victims of torture in the world, it is remarkable that diagnoses of trauma sequelae are made without studying these most severe forms of trauma in adult experience.

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